DOCUMENT RESUME

ED 287 559 PS 016 809

TITLE	AIDS and Young Children: Emerging Issues. Hearing before the Select Committee on Children, Youth, and Families. House of Representatives, One Hundredth Congress, First Session. Hearing Held in Berkeley, California.
INSTITUTION	Congress of the U.S., Washington, DC. House Select Committee on Children, Youth, and Families.
PUB DATE	21 Feb 87
NOTE	190p.; Many pages contain small print.
AVAILABLE FROM	Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402 (Stock No. 052-070-06339-4, $5.50).
PUB TYPE	Legal/Legislative/Regulatory Materials (090)
EDRS PRICE	MF01/PC08 Plus Postage.
DESCRIPTORS	*Acquired Immune Deficiency Syndrome; Child Abuse; Children; *Communicable Diseases; Costs; *Delivery Systems; Ethnic Groups; *Health Education; *Health Services; Hearings; High Risk Persons; Incidence; Intervention; Neonates; *Prevention
IDENTIFIERS	*Child Health; Hemophilia

ABSTRACT

This field hearing in Berkeley, California examined: (1) the increasing incidence of babies born with, or at risk of contracting, Acquired Immune Deficiency Syndrome (AIDS); (2) the ability of health and social service systems to care for AIDS-infected infants and children and their families; and (3) prevention efforts to reduce the spread of AIDS. Testimony given by medical and social service personnel centered on (1) the current and expected incidence of AIDS and AIDS Related Complex (ARC) among children, women, and heterosexual adults in San Francisco; (2) the dimensions of AIDS throughout the world, in the United States, and in Alameda County; (3) implications of the incidence of AIDS in children and youth; (4) initial strategies for prevention and treatment; (5) issues facing hemophiliac children who have AIDS or have been exposed to the virus; (6) large increases in reports of child abuse and neglect in the past 5 years due to substance abuse and sexual molestation and the fact that children who are victims of this abuse are at high risk for AIDS; (7) issues concerning ethnic minority children and AIDS; (8) implications of the recent births of four seropositive infants for treatment and costs; and, in conclusion, (9) the need to educate children and youth about AIDS in a developmentally appropriate manner. (RH)

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AIDS AND YOUNG CHILDREN: EMERGING ISSUES

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ED287559

HEARING

BEFORE THE

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES HOUSE OF REPRESENTATIVES

ONE HUNDREDTH CONGRESS

FIRST SESSION

HEARING HELD IN BERKELEY, CA, FEBRUARY 21, 1987

Printed for the use of the
Select Committee on Children, Youth, and Families

PS016809

72-324

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AIDS AND YOUNG CHILDREN: EMERGING ISSUES

SATURDAY, FEBRUARY 21, 1987

House of Representatives,
Select Committee on Children, Youth, and Families,
Berkeley, CA.

The committee met, pursuant to notice, at 10:00 a.m., in the Alta Bates Hospital Auditorium, Berkeley, California, the Hon. George Miller presiding.

Members present: Representatives Miller, Boxer, Dellums, and Stark.

Staff present: Ann Rosewater, staff director; Karabelle Pizzigati, professional staff; Spencer Hagen Kelly, minority research staff.

Chairman Miller. The hearing of the House Select Committee on Children, Youth, and Families will come to order.

The purpose of conducting this meeting today in the San Francisco Bay Area is to hear testimony on the growing AIDS crisis and its impact on children.

The American public has only recently begun to learn the ominous consequences of this disease. When we hear the word AIDS, we immediately think of a health problem which has affected the adult population, and we have justifiably begun to treat AIDS as America's number one public health concern.

It is increasingly clear that AIDS is spreading rapidly among the heterosexual population, and that there are life-threatening implications for babies, young children, and adolescents. We generally do not think of AIDS as a disease affecting many young children because it is primarily transmitted through sexual contact and intravenous drug use. Our everyday perceptions are wrong. AIDS is not a disease limited to adults. It threatens to kill thousands of children, many of them very young.

Tragically, there is very little we know about it. Even worse, we are inadequately prepared to take care of those babies who already have AIDS, let alone many more who are likely to contract it in the near future. This problem has surfaced most acutely on the East Coast, and the West has yet to see the overwhelming numbers of children who are infected with AIDS or to experience the devastating problems of finding and financing appropriate care for those sick babies.

In just the past few weeks, we have learned that the number of West Coast children who have AIDS or who are at risk has quickly grown. This presents enormous challenges to public policymakers as well as to the average citizen.

The Bay Area has mobilized to educate the community about the nature of this disease, its effects on adults, and what steps can be taken to prevent it. I am pleased that in my own county we are able to deal with educating children with AIDS in a positive and non-disruptive manner.

It is now essential that a similar community-wide effort be made to provide humane care and treatment for AIDS-infected children and their families, to find the most cost-effective manner in which we can provide these services, and to make every effort to educate young people as well as adults about the facts of this disease and its prevention.

To assist us in understanding the complexities of AIDS and its impact on children, we will hear today from experts in the field. We will learn what is known about the transmission of AIDS to young children, what kind of care is necessary and appropriate for young AIDS victims, and what alternatives exist to help families pay for the enormous costs of this treatment.

I am delighted today that the Select Committee is joined by my three colleagues from the Bay Area. Each and every one of the people on this panel is going to have a rather significant responsibility in dealing with the question of AIDS in our society.

Congresswoman Boxer, who is also a member of the Select Committee, and a colleague of mine on the Budget Committee, will be leading an effort in the Budget Committee to make sure that we adequately fund all of the programs, be they educational or research or care, that are necessary for us to deal with the impact of AIDS in our society. She will also be confronting the problems of AIDS within the military programs of this country as will Ron Dellums, who is the subcommittee chairman on the military committee in the Congress, where for some time they have been trying to put together a humane and decent treatment program for the treatment of AIDS within the military service. Pete Stark, who is the subcommittee chairman on the House Ways and Means Committee on Health, will be trying to do two things: one, to make sure that we have adequate resources within the health care fields so that those affected by AIDS will have an opportunity to receive the best treatment, and also to figure out how we finance that so that those institutions that must confront this serious problem are able to deliver that treatment to the widest number of people in need.

[Opening remarks of Congressman George Miller follow:]

OPENING REMARKS OF CONGRESSMAN GEORGE MILLER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA, AND CHAIRMAN, SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES

The Select Committee on Children, Youth, and Families is meeting in the Bay Area today to hear testimony on the growing AIDS crisis and its impact on children.

The American public has only recently begun to learn the ominous consequences of this disease. When we hear the word "AIDS," we immediately think of a health problem which has affected the adult population, and we have justifiably begun to treat AIDS as America's number one public health concern.

Although adults constitute the majority of individuals with AIDS, it is increasingly clear that with AIDS spreading rapidly among the heterosexual population, there are life-threatening implications for babies, young children and adolescents.

We generally do not think of AIDS as a disease affecting many young children because it is primarily transmitted through sexual contact and intravenous drug use.

But our everyday perceptions are wrong.

AIDS is not a disease limited to adults; it threatens to kill thousands of children, many of them very young.

Tragically, there is very little that we know about it.

Even worse, we are inadequately prepared to take care of those babies who already have AIDS, let alone the many more who are likely to contract it in the near future.

This problem has surfaced most acutely on the East Coast. The West has yet to see overwhelming numbers of children who are infected with AIDS, or to experience the devastating problems of finding and financing appropriate care for these sick babies. But in just the past few weeks, we have learned that the number of West Coast children who have AIDS or are at risk has grown quickly.

This presents enormous challenges for public policymakers as well as for average citizens.

The Bay Area has mobilized to educate the community about the nature of this disease, its effects on adults, and what steps can be taken to prevent it. I am pleased that in Contra Costa County we have been able to deal with educating children with AIDS in a positive and nondisruptive manner.

Now it is essential that a similar community-wide effort be made to provide humane care and treatment for AIDS-infected children and their families, to find the most cost-effective manner in which to provide these services, and to make every effort to educate young people as well as adults about the facts of this disease and its prevention.

To assist us in understanding more about the complexities of AIDS and its impact on children, we will hear today from experts in this field. We will learn what is known about the transmission of AIDS to young children, what kind of care is necessary and appropriate for young AIDS victims, and what alternatives exist to help families pay the enormous costs of AIDS treatment.

I would like at this time to open it up to my colleagues for any comments that they may have. Barbara, I recognize you first.

Mrs. Boxer. Thank you very much, Mr. Chairman.

I am very pleased that you called us together today for this very important hearing. Your concern about children is really legend, and if it was not for Congressman Miller, we never would have had a Select Committee on Children, Youth, and Families. This is the only committee in the House that takes a look at the condition of children, youth, and families, and when you think about what our responsibilities are, certainly to that population, it is enormous, and we always thank him for that contribution.

In terms of AIDS, I am heading this task force, of which Mr. Miller is a part on the Budget Committee, to make sure that we fund adequately the effort on AIDS. It has to be an enormous effort because we are in an enormous epidemic.

I would just say lastly that the Budget Committee just held field hearings throughout the country, and AIDS was one of the primary topics, and members of that committee from all over the country are now becoming aware of this horrendous problem.

Mr. Chairman, this hearing today is going to bring it home even further as we look at its effects on children, and I thank you.

Chairman Miller. Congressman Dellums?

STATEMENT OF HON. RONALD V. DELLUMS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. Dellums. Thank you very much.

Mr. Chairman and members of the committee, let me first welcome all of you to the 8th Congressional District, a place that I call an oasis of sanity in a world that sometimes appears to be going mad.

Let me express my appreciation for this opportunity to join today's hearing, but, more importantly, however, let me express my appreciation for the committee's concern with the tragedy of Acquired Immune Deficiency Syndrome. The emphasis on the effects of AIDS on our youth is critical to our nation's future.

While the emergence of the AIDS problem in pre-adolescent children is small in number, it is of a greater magnitude in human terms. The Centers for Disease Control have reported some 420 cases of pediatric AIDS, but members of our health care community believe that the number is higher. Even the Centers for Disease Control expect the numbers of reported cases to double within another year. The human cost is unbelievable.

The majority of children born with AIDS die within three years. During their brief life span, these children and their parents encounter tremendous difficulty obtaining adequate care. If they are lucky enough to exceed the expected three year time span, these children face similarly insurmountable obstacles as they seek education, peer relationships, community acceptance, and social services.

The circumstances ultimately end in tragedy, and I would ask rhetorically, must we force them to endure such tremendous adversity while they live? In the general population, more than 29,000 persons have contracted AIDS. By the end of 1991, the Public Health Service estimates that more than 279,000 cases of AIDS will have occurred with more than 179,000 deaths.

While statistically few of these numbers are children, the actions that we take today will determine the future course of this deadly disease as our children become young adults.

Then, I would add that we must develop a profound interest in alleviating the problem of AIDS in the general population so that our children will not become tomorrow's AIDS victims. We must obviously include a major educational effort as a component of an effective statute to combat AIDS. Even our Surgeon General, widely known for his conservative views, has concluded, and I quote,

> Those of us who are parents, educators, community leaders, indeed, all adults, cannot disregard the responsibility to educate our young. The need is critical and the price of neglect is high. The lives of our young people depend upon our fulfilling our responsibility.

The Congressional Office of Technology Assessment echoes the view that prevention through education provides the primary means for restricting the spread of this disease. Effective treatment and especially prevention of infection through vaccines represent a difficult technological objective yet to be achieved. This is a startling statement in this modern era of high-tech medical cures.

Given the lack of medical-technical means to deal with AIDS, we must view educational efforts as an extension of the medical treatment program, in this case, abatement by prevention of infection.

Let us consider educational strategies as an urgent priority and, equally important, in the urgent priority for both young and old alike is adequate funding for long-term care for AIDS victims. The

House of Representatives Committee on Energy in Congress stated two years ago that,

> The American health care system is already strained by pressures branching from the growing number of uninsured people to the decline in adequacy of federal programs. Community public hospitals, who are left with the responsibility of caring for all of those without insurance may be unable to bear the responsibility of increasing AIDS cases.

Mr. Chairman, members of the committee, I would further state that the American health care system is in crisis. We cannot exacerbate this problem further by failing to enact emergency measures, to fund long-term care for AIDS patients. This type of long-term program may be difficult to enact, but we must not allow ourselves to be deterred.

To paraphrase our distinguished colleague, the gentleman from California, Mr. Waxman, AIDS is not a political disease but a public health catastrophe.

Research may be another political battleground, but we must act to dramatically increase the funding available for AIDS research. The record of the Congress on this matter is one of heroic resistance to the cruel calculations of its Administration that in 1985 vetoed funding legislation for federal health research institutes. We must continue to appropriate more than this Administration will ever be willing to spend, for as Caitlin Ryan, Director of an AIDS education program in Washington, D.C., recently stated,

> We're going to look back at this in five years and we're going to be shocked at what did and did not happen.

There is one additional aspect of AIDS we must address for the sake of both affected children and adults, and that is protecting the civil rights of the AIDS victims. As the number of cases rise, so do the numbers of actions by individuals and institutions which infringe upon the rights of affected children.

Whether we are discussing mandatory screening for urban single men by insurance companies, denial of public assistance, or use of community facilities or refusal to provide health care or even undertaking services, we must view assault on civil rights on one class of society as a threat to all of us.

We must also consider the fact that such denials are an even greater setback for anyone who is seriously ill, especially the child who cannot attend school or participate in community activities.

I am dismayed, Mr. Chairman, by the climate of hatred and ostracism as well as the big misconception about the transmission of AIDS. It is our federal responsibility to act to affirmatively guarantee the civil rights of AIDS patients, young or old.

Mr. Chairman, this concludes my statement. I thank you for giving me the opportunity to read it into the record. Thank you again for the opportunity to participate in this significant undertaking, to which I pledge my unwavering support.

May I just add affirmatively that, as you know, the position of these hearings were to be held on Friday, and we were scheduled to be with you, and then the Congress decided that we were going to have to vote and then ended up not having to vote, and we moved it over to Saturday and now my schedule has some conflicts. I will be able to be with you until around 11. My staff person will be here during the course of the day. I am sure that you will make the proceedings of these hearings available to me as I wish to study them very carefully.

I thank all my colleagues.

[Prepared statement of Congressman Ronald V. Dellums follows:]

PREPARED STATEMENT OF HON. RONALD V. DELLUMS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. Chairman and members of the committee: I would like to express my appreciation for this opportunity to join today's hearing. Most importantly, however, let me express my appreciation for the committee's concern with the tragedy of Acquired Immune Deficiency Syndrome (AIDS). Your emphasis on the effects of AIDS on our youth is critical to our Nation's future.

The dimensions of the AIDS problem in pre-adolescent children, while small in number, are of great magnitude in human terms. The centers for disease control have reported some four hundred twenty cases of pediatric AIDS, but members of our health care community believe that the actual numbers are much higher. Even the centers for disease control expect the number of reported cases to double within another year.

The human cost is unbelievable—the majority of children born with AIDS die within three years. During their brief life spans, these children, and their parents, encounter tremendous difficulty obtaining adequate care. If they are lucky enough to exceed the expected three-year life span, these children face seemingly insurmountable obstacles as they seek education, peer relationships, community acceptance and social services. Their circumstances ultimately end in tragedy—must we force them to endure such tremendous adversity while they live?

In the general population, more than twenty-nine thousand persons have contracted AIDS. By the end of 1991, the public health service estimates that more than 279,000 cases of AIDS will have occurred, with more than 179,000 deaths. While statistically few of these number are children, the actions that we take today will determine the future course of this deadly disease as our children become young adults. I propose, Mr. Chairman, that we have a profound interest in alleviating the problem of AIDS in the general population, so that our children will not become tommorrow's AIDS victims. We must extend our sphere of interest, Mr. Chairman, to include consideration of measures affecting not only children and youth, but the family that is comprised of our entire society.

"Education about AIDS should start in early elementary school and at home so that children can grow up knowing the behavior to avoid to protect themselves from the AIDS virus."—Surgeon General's Report on Acquired Immune Deficiency Syndrome, 1986

"Sex educators face a powerful array of detractors and doubters: Fundamentalist and Roman Catholic leaders, antiabortionists, opponents of the gay lobby, psychologists who worry about the impact of AIDS messages on the young, blacks who consider sex education racist, and even a few capitalists who think that school clinics offering birth control information should be turned over to private enterprise."—Time Magazine, November 24, 1986

We must obviously include a major educational effort as a component of an effective strategy to combat AIDS. Even our Surgeon General, widely known for his conservative views, has concluded that, "those of us who are parents, educators and community leaders, indeed all adults, cannot disregard the responsibility to educate our young. The need is critical and the price of neglect is high. The lives of our young people depend on our fulfilling our responsibility."

The Congressional Office of Technology Assessment echoes the view that "prevention through education remains the primary means of restricting the spread of this disease. Effective treatment and especially prevention of infection through vaccines represent difficult technical objectives yet to be achieved." This is a startling statement in this modern era of high-tech medical cures. Given the lack of medical-technical means to deal with AIDS, we must view educational efforts as an extension of the medical treatment process—in this case, abatement by prevention of infection. I ask you to consider educational strategies as an urgent priority.

An equally important, indeed urgent, priority for both young and old alike is adequate funding of long-term care for AIDS victims. The House of Representatives Committee on Energy and Commerce stated two years ago that "the American health care system is already strained by pressures ranging from the growing number of uninsured people to the declining adequacy of Federal programs. Many public hospitals—who are left with the responsibility of caring for all those without insurance—may be unable to bear the responsibility of increasing AIDS cases."

Mr. Chairman, I would state further that the American health care system is in crisis. We cannot exacerbate this problem further by failing to enact emergency measures to fund long-term care for AIDS patients. This type of long-term program may be difficult to enact, but we must not allow ourselves to be deterred. To paraphrase our distinguished colleague, Henry Waxman, AIDS is not a political disease but a public health catastrophe.

Research may be another political battleground, but we must act to drastically increase the funding available for AIDS research. The record of the Congress on this matter is one of heroic resistance to the cruel calculations of an administration that in 1985 vetoed funding legislation for Federal health research institutes. We must continue to appropriate more than this administration will ever be willing to spend, for as Caitlin Ryan, director of an AIDS ecducation fund in Washington, D.C., recently stated "we're going to look back at this in five years and we're going to be shocked at what did and did not happen."

There is one additional aspect of AIDS which we must address, for the sake of both affected children and adults—protecting the civil rights of AIDS victims. As the number of cases rises, so do the number of actions by individuals and institutions which infringe on the rights of affected persons. Whether we are discussing mandatory screening of urban single men by insurance companies, denials of public assistance or use of community facilities, or refusal to provide health care or even undertaking services, we must view assaults on the civil rights of one class of society as a threat to us all. We must also consider the fact that such denials are an even greater setback for someone who is seriously ill—especially the child who cannot attend school, or participate in community activities. I am sickened by a climate of hatred and ostracism born of ignorant misconceptions about the transmission of AIDS. It is our Federal responsibility to act to affirmatively guarantee the civil rights of AIDS patients, young or old.

This concludes my statement, Mr. Chairman. Thank you again for the opportunity to participate in this significant undertaking, to which I pledge my unwavering support.

Chairman **Miller**. Thank you very much.
Congressman Stark?

STATEMENT OF HON. FORTNEY H. STARK, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. **Stark**. Thank you, George, and Barbara, for convening these hearings and the work that you put in on the Select Committee on Children, Youth, and Families.

In the legislative arena where the currency of success is legislation, those people who serve on the Select Committee do not get paid; it is a labor of love, and they can act as a catalyst and often bring to the attention of others on other committees the urgent problems, and for that I thank you.

To Ron Dellums, my thanks for inviting us here to the arctic region of Oakland, and to the hospital in which my three daughters were born. Born in the year when polio was passed and AIDS was not present, and as a parent in those days, I now look back and see what an easy time their mother and I had.

My concern is a very harsh-sounding concern, but it is cost. Chairing the committee that has to deal with an Administration which, in the two years that I have chaired the health committee, has tried to cut $10 and $15 and $20 billion out of the medical delivery system, is not a pleasant job. We are faced with that again, and it is hospitals like this that bear the cost of all of the medical care that goes unpaid, because people cannot afford it, and which is contributed as a charitable contribution, and we see looming on the horizon the costs of an indeterminate catastrophe.

The President has seen fit, after we dragged him kicking and screaming, to support a catastrophic insurance bill, which we hope to add to the benefits of Medicare this year. But that barely touches the surface, and to use the word catastrophic for that, to me, is overkill.

But the potential cost impact from an unchecked epidemic in the making boggles our minds, and, George, I am here to learn, and I am scared, and I thank you for inviting me to sit in with you today.

Chairman **Miller**. Thank you.

Let me say to the audience, all of my colleagues have been generous enough to give us a portion of their morning. When I talked to them some weeks ago, these hearings originally were going to be on Friday and then had to be changed. So, I would hope that you would understand that they have conflicts, but they have all come to be present for some portion of the morning.

I want to thank Alta Bates Hospital and recognize Carl Smith, who is the vice-president for public affairs. Carl, I know you want to provide us with a welcome. I just want to say that Alta Bates has been a great help to us in setting up this hearing, but also to the community in addressing this problem.

We appreciate that.

STATEMENT OF CARL SMITH, VICE PRESIDENT PUBLIC AFFAIRS, ALTA BATES CORP., BERKELEY, CA

Mr. **Carl Smith**. Thank you.

My name is Carl Smith. I am Vice-President of Public Affairs at Alta Bates Corporation, which is the parent of your host, Alta Bates Hospital, and I want to thank the committee for allowing us to host this, and we are pleased at the opportunity to have this hearing.

As health care professionals, I repeatedly tell everyone who will listen that we are terrified of the potential impact of AIDS on this facility, on our people who try to take care of patients, and on our out-patient clinics. It is becoming pervasive, and we are very pleased that it is getting noticed by congressional committees such as yours, but probably more importantly we are also pleased that you are conducting a hearing on children and AIDS to help us and everybody else demystify the fact that AIDS is not simply a homosexual disease.

I simply would like to thank you again for having it here, and if there is anything we can do, please let us know.

Chairman **Miller**. Thank you.

The first panel that the committee will hear from will be made up of Dr. Moses Grossman, who, among a lot of other things, is now the Chairman of the San Francisco Health Department Task Force on Pediatric and Perinatal AIDS; Dr. Robert Benjamin, who is the Chief, Bureau of Communicable Diseases for the Alameda County Department of Community Health Services; John Williams, who is the Executive Director of Children's Hospital at Stanford in Palo Alto; and Jean McIntosh, who is the Assistant Director for Los Angeles County Department of Children's Services.

Would you come forward, please? We will recognize you in that order. I know, Dr. Grossman, you have to leave after your testimony. So, we will interrupt to ask you questions and then we will let the rest of the panel testify and then allow for questions from members of the delegation here.

So, come forward. Welcome to the committee. You proceed in the manner in which you are most comfortable. Your written statements will be placed in the record in their entirety, and to the extent that you want to summarize, you feel free to go ahead and do that.

Let me also say that as with most hearings, we have many more people who wanted to testify than we had time for. We will keep the record open for two weeks for people who want to submit written testimony to the committee. If there is something that is said or that you disagree with or you think should be elaborated on, we would encourage you to make that known to the committee and you can send it to us in the committee office in Washington.

[Prepared statement of Carl Smith follows:]

Prepared Statement of Carl Smith, Vice President of Public Affairs for Alta Bates Corporation, Berkeley, Ca.

GOOD MORNING.

MY NAME IS CARL SMITH, VICE PRESIDENT OF PUBLIC AFFAIRS FOR ALTA BATES CORPORATION. ALTA BATES CORPORATION IS A NOT-FOR-PROFIT HEALTH CARE COMPANY BASED IN BERKELEY, THAT OWNS AND OPERATES THREE HOSPITALS, APPROXIMATELY 30 LONG-TERM CARE FACILITIES, AND SEVERAL OTHER RELATED HEALTH SERVICES. AS THE HOST OF THIS HEARING, I WOULD LIKE TO THANK THE COMMITTEE FOR CHOOSING US AS THE SITE TO CONDUCT THIS EVENT. BUT MOST IMPORTANTLY, WE APPRECIATE THE COMMITTEES' OBVIOUS CONCERN FOR CHILDREN AND THEIR HEALTH AND WELL-BEING.

AS HEALTH CARE PROFESSIONALS, WE ARE TERRIFIED OF THE POTENTIAL IMPACT OF AIDS ON BOTH CHILDREN AND THE GENERAL PUBLIC. NO HEALTH CARE PROFESSIONAL IS ABLE TO AVOID ADDRESSING THE HEALTH CARE NEEDS OF AIDS PATIENTS BECAUSE THE DISEASE IS VIRTUALLY EVERYWHERE. WE THANK THE COMMITTEE FOR THEIR INTEREST IN THIS ISSUE AND WILL PRESENT TESTIMONY LATER ON ON WHAT WE ARE DOING HERE AT ALTA BATES CORPORATION TO ADDRESS THIS HEALTH CARE CONCERN.

THANK YOU.

Chairman MILLER. Dr. Grossman.

STATEMENT OF DR. MOSES GROSSMAN, PROFESSOR OF PEDIATRICS AND VICE CHAIRMAN, DEPARTMENT OF PEDIATRICS, UNIVERSITY OF CALIFORNIA AT SAN FRANCISCO; CHIEF OF PEDIATRICS, SAN FRANCISCO GENERAL HOSPITAL; CHAIRMAN, SAN FRANCISCO HEALTH DEPARTMENT TASK FORCE ON PEDIATRIC AND PERINATAL AIDS; MEMBER, MAYOR'S TASK FORCE ON AIDS, SAN FRANCISCO, CA

Dr. GROSSMAN. Thank you very much for the opportunity to be here, Congressman Miller.

Chairman MILLER. Pull all those microphones closer to you. All these people want to hear what you have to say.

Dr. GROSSMAN. Thank you for the opportunity to be here. I really appreciate your having these hearings. I was pleased that you organized the committee. As an advocate for children myself, I am glad to have a committee in Congress dealing with children and I am particularly pleased that you are dealing with the subject of pediatric AIDS.

AIDS is a phenomenal problem in our country and in the world. It is really epidemic and because the first wave that occurred among adults, children are apt to be forgotten. If you look at CDC numbers, the number seems small. The last number I saw was 437.

I would like to echo those who said before me that that number is under-represented in a very serious way. CDC for epidemiologic purposes has a very strict and very narrow definition of AIDS, for epidemiological purposes, it is fair enough; but if you think about children who need care and how many of them there are, as of today, there are many, many more than that number.

Furthermore, it has become very clear that heterosexual transmission is here, not just in Africa, not just in Belgium, but in the United States. It is here to grow, I think, and the best analogy that somebody suggested to me, and I thought I would repeat it for this committee, as far as heterosexual transmission is, if you go fishing and you fish in a pool where there is only one fish and you fish for an hour, you will not catch anything, but if you fish in a pool where there are a thousand fish, you are going to catch some fish, and so far there has been very little fish in the AIDS heterosexual pool, but the number is growing.

Pretty soon, we will see a thousand fish caught, and that means it is going to affect children, which it has not very much so far.

My own personal involvement began approximately a year ago; the San Francisco Health Department asked me to chair the Task Force on Pediatric and Perinatal AIDS. We have done quite a lot of work during that year, and I thought I would share very briefly some of the things we have done.

We thought that things we needed to address were perinatal AIDS. (We finished that, and I will tell you about it.) AIDS in the schools. AIDS among adolescents and sexual abuse and AIDS. So, we have tackled these four problems.

As far as perinatal AIDS, we thought that the work should start well before women become pregnant. There should be widespread education first among women at high risk, but increasingly among all women. Women need to know that if they think they might have AIDS, pregnancy is a very serious problem not only for the baby but for the pregnant woman. Her own immune system is much more affected if she is pregnant than if she is not, and her disease is far more likely to progress.

So, she may want to take particular steps not to get pregnant if she knows that she is antibody positive. So, the first step is encouraging women to get tested before they consider pregnancy and to think about it carefully.

We thought that women in high-risk categories (and here I need to spell out to health providers exactly who they are: (1) those with sexual contacts with infected men, (2) those who are IV drug users, and (3) also those many women who know that they are high-risk and do not wish to tell anybody why), should get tested in the first trimester, when there is still an opportunity to choose whether they wish to continue the pregnancy or not. If they are negative when first tested, we think they should get retested in the third trimester if they are in the high-risk category.

Now, we come to a problem which is serious, particularly in California. I agree with Congressman Dellums about protecting civil rights, but some of the laws that the legislature has passed about confidentiality inhibit the transmission of information between obstetrician and pediatrician and delivery room personnel as far as the management of the event of delivery is concerned as well as managing the baby in the nursery.

We did write some guidelines about how to do that in consultation with the Juvenile Court and a group of attorneys, but that is a difficult area. We also wrote guidelines about foster care and how to deal with foster parents and what to do about adopting parents. I will not belabor these issues, except to say these guidelines exist and they are in the testimony I submitted to you.

This information was developed as one of the earliest documents in our country and will soon be published in the literature for all to read.

Our school guidelines are not nearly as innovative. They are straight-forward. They essentially state that education for school children is very important and the San Francisco Health Department and the school board have worked all summer and developed a curriculum for the schools, starting in junior high school. That may be too late. We may need to start in elementary school, in terms children can understand, and then build that understanding about infectious diseases, about sexuality, sexual lifestyles, till we get to high school, so the knowledge will protect them from getting infected. This education is happening now.

Secondly, we organized a committee which places children in school. It is a combined committee of the Health Department and school department, but the one point I wanted to make to you is that the final decision lies with the Director of Health, not with the School Board. I hope that will take it out of politics. So far, it has, but the numbers so far are very small and not enough to inflame public interest.

The third area that we dealt with and just finished (in fact, our work has not yet been approved by the Health Commission, but I did submit a draft for the committee) is guidelines for adolescents.

There are many adolescents at high risk in San Francisco and around the nation. You go out on Larkin Street, and you will see boy and girl prostitutes, and you know that this is an area of high risk.

There is a lot of discussion about how to deal with this group of youngsters. I have two points to make. One is that education should take place not only in the school but on the street because these are kids who do not go to school, and I think educational information efforts need to be provided.

Thanks to some efforts by the next speaker, Dr. Benjamin, we finally are able to do a prevalence study. We have absolutely no idea about how many youths are infected, but now it is possible to do a prevalence study without identifying anybody, just to give us an idea. Is the percentage of youths with antibodies two percent, is it ten percent. So, after awhile, we will know. The study just started. After much debate, we have decided not to do any involuntary testing in adolescents.

This is a highly contentious area when it comes to adolescents in institutions. There are no similar guidelines in the United States on how to deal with jailed prisoners. But you have our draft in your packet and you can read it at your leisure.

The final area is the area of sexual abuse. There are verbal reports not published, that there are three children who have been infected with AIDS while being sexually abused.

We are now also conducting a prevalence study in this area. My institution sees 75 children every month who have been sexually abused, and we are studying them now to see whether any of them have become infected. We have not yet prepared any guidelines about sexual abuse and AIDS.

So, that essentially summarizes my comments. I am grateful that you are looking into pediatric AIDS and hope that you will continue having Congress focus on this issue.

[Prepared statement of Moses Grossman, M.D., follows:]

PREPARED STATEMENT OF MOSES GROSSMAN, M.D., CHAIRMAN OF THE SAN FRANCISCO HEALTH DEPARTMENT TASK FORCE PROFESSOR OF PEDIATRICS, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, CA

San Francisco has had a major problem with AIDS among its large gay population. 2780 cases were reported through 1-8-1987 of which 1623 have died. By contrast so far only seven children have been reported in San Francisco. Beyond these seven reported cases that meet the narrow definition of the CDC there are undoubtedly a few more children with AIDS, a few with ARC, and perhaps another dozen born to infected mothers but asymptomatic for the moment. We project 25-40 babies to be born to infected mothers in 1987. Beyond that we expect that heterosexual transmission of the infection will become increasingly important and the number of infants with AIDS will rise.

The San Francisco Health Department Task Force on Perinatal and Pediatric AIDS which I chair has been working on guidelines for the handling of this infection in children.

I. Perinatal Guidelines (attachment)

These guidelines (now implemented) recommend intensive efforts to educate women in the high risk group for HIV infection about the effects of pregnancy on their own health (if they are infected) and on their infant.

They further call for the testing of pregnant women in the high risk category (high risk category includes women who are IV drug users, women who are sexual partners of infected men, recipients of blood and blood products between the year 1979 and 1985 and those who themselves feel that their sexual behavior places them at risk for HIV infection) for HIV antibodies with their consent during the first and third trimester of pregnancy. Those who are antibody positive should be counselled about the risk involved for themselves and their unborn infant. The guidelines also deal with foster care and adoption issues. Our community as yet has had very little experience in placing these children in out of home settings. The Department of Social Services has initiated an educational program for foster parents on this subject. The complete guidelines are attached.

Education - School policy (attached) approved by both Health Commission and School Board calls for an educational curriculum for the school which is now being implemented. Placement of infected children over the age of three years in the school is in the hands of a professional advisory committee; the final approval is in the hands of the Director of Health. We recommended that infected children younger than three years not be placed in day care centers, in order to protect them from infections rampant in such centers. This does create a problem of child care for these young children which will need to be addressed.

Adolescent Issues - Many youths of both sexes are at high risk of acquiring an HIV infection. We feel that very strong educational efforts are necessary not only in the school but also on the street. After much debate and thought we recommended against involuntary testing for youth in any setting. Voluntary testing with consent and counselling should be provided to youngsters at risk who are symptomatic. Such testing must be confidential in every respect.

These recommendations are made in the light of present knowledge and the lack of meaningful medical intervention for antibody positive but asymptomatic individuals. However because of public concern and liability issues for operators of various adolescent shelters testing of adolescents in institutions and shelters will continue being an issue.

The adolescent guidelines are in draft form at present, approved by the Task Force but not yet presented to the Director of Health or the Health Commission.

Child Abuse - There are verbal reports of three children allegedly infected in the course of being sexually abused. We are conducting a research study in this are and have not yet formulated any guidelines.

Conclusion - Pediatric AIDS is a different disease than the adult infection and the public health and policy issues are also different. While numerically and percentagewise small, compared to the problem in adults, the number of infected children is undoubtedly significantly larger than those reported in the official statistics and based on the strict and narrow CDC definition. Heterosexual transmission is expected to increase these numbers very significantly. Children and families with this disease as well as the population at large would benefit by the development of public policy and allocation of necessary resources. If a National Congressional Commission on AIDS is organized, as has been suggested, Pediatric AIDS should be an important part of the agenda.

cc: David Werdegar, M.D., Director of Health
Philip Lee, M.D. President of Health Commission
Merle Sande, M.D., Chairman, Mayor's Task Force

SAN FRANCISCO EPIDEMIOLOGIC BULLETIN

CITY AND COUNTY OF SAN FRANCISCO • DEPARTMENT OF PUBLIC HEALTH • BUREAU OF COMMUNICABLE DISEASE CONTROL

Vol. 2, Supplement 1 April 1986

Guidelines for Control of Perinatally Transmitted Human T-Lymphotropic Virus-Type III/Lymphadenopathy-Associated Virus Infection and Care of Infected Mothers, Infants, and Children

City and County of San Francisco
Department of Public Health
Perinatal and Pediatric AIDS Advisory Committee

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The information and recommendations contained in this document were developed and compiled by the Perinatal and Pediatric AIDS Advisory Committee, a special task force of the Department of Public Health (DPH), City and County of San Francisco, which included representatives of the Departments of Obstetrics, Gynecology, and Reproductive Sciences, Medicine, and Pediatrics, and the AIDS Activities Unit, San Francisco General Hospital, University of California, San Francisco; the San Francisco Medical Society; the American Academy of Pediatrics; the San Francisco Gynecologic Society; the San Francisco AIDS Foundation; and the Department of Social Services (DSS), the City Attorney's Office, and the Juvenile Court of the City and County of San Francisco.

These recommendations apply to all infants, children, and women of child-bearing age known to be infected or at high risk of being infected with human T-lymphotropic virus-type III/lymphadenopathy-associated virus (HTLV-.II/LAV). This includes persons with Centers for Disease Control (CDC)-defined acquired immunodeficency syndrome (AIDS), persons with lesser clinical manifestations of HTLV-III/LAV infection such as AIDS-related complex (ARC), and persons with asymptomatic HTLV-III/LAV infection.

These guidelines are intended to supplement previously published national guidelines for the education and foster care of HTLV-III/LAV-infected children[1] (Attachment I) and for the prevention of perinatal HTLV-III/LAV infection (Attachment II).[2] They were approved by the Health Commission on February 4, 1986, and are being distributed to health care providers, clinics, hospitals, and interested individuals.

BACKGROUND

Perinatal HTLV-III/LAV Infection and Pediatric AIDS

The transmission of HTLV-III/LAV from infected mothers to infants, either *in utero* or perinatally, has been well established.[3-12] Infection in these infants can be asymptomatic or cause a variety of clinical syndromes including AIDS.[13] It is not, however, conclusively known what proportion of infants exposed *in utero* or perinatally will become infected and what proportion of infected infants will develop clinical disease.[2] As of December 1, 1985, 217 cases of pediatric AIDS had been reported to CDC (CDC, unpublished data). Forty-eight percent of these children were born to intravenous-drug-using mothers, 17 percent to Haitians, and 10 percent to mothers who either had AIDS or were sexual partners of men with AIDS or at risk for AIDS. An additional 39 (18 percent) children were infected through transfusions of infected blood or blood products, and 13 (6 percent) had unknown sources of infection. Thus, 165 (76 percent) of the cases had been exposed to HTLV-III/LAV *in utero* or perinatally.

Perinatally infected infants who go on to develop AIDS first develop symptoms at a median age of four months, and approximately one-half of these infants will be diagnosed as having AIDS by their first birthday.[13] Typical prodromal symptoms include failure to thrive, recurrent or persistent thrush, chronic interstitial pneumonitis, hepatosplenomegaly, chronic or recurrent diarrhea, lymphadenopathy, and severe recurrent bacterial infections such as sepsis and meningitis. When frank clinical AIDS develops in these patients, the most common diagnosis is *Pneumocystis carinii* pneumonia (62 percent) and the second most common are other opportunistic infections without Kaposi's sarcoma or *Pneumocystis carinii* pneumonia (33 percent).[13]

HTLV-III/LAV Infection in Women of Child-Bearing Age

In the United States, approximately 7 percent of adult cases of AIDS involve women. Fifty-three percent of these women are intravenous drug users, 15 percent are sexual partners of men in risk groups (primarily heterosexual intravenous drug users), and 9 percent have received infected blood or blood products. Eighty percent are between 20 and 49 years old. Twenty-two percent of these women are white, 55 percent black, and 23 percent Hispanic (CDC, unpublished data). In San Francisco, as of January 31, 1986, there had been 10 cases of

AIDS reported in adult women. Three of these women were intravenous drug users, one was a sexual partner of a man in a high prevalence group, four had received transfusions, and two had no identified risk. Four were between 20 and 49 years old; two of these were white, one black and one Asian.

HTLV-III/LAV Transmission in Households

None of the identified cases of HTLV-III/LAV infection in the United States are known to have been transmitted in school, day-care, or foster-care settings or through casual person-to-person contact.[1] Other than sexual partners of HTLV-III/LAV-infected patients, infants born to infected mothers, or a single case involving nosocomial transmission from a child to a mother providing nursing care[14], none of the family members of the over 17,000 AIDS patients reported to CDC have developed AIDS. Five studies of family members of patients with HTLV-III/LAV infection have failed to demonstrate HTLV-III/LAV transmission to adults who are not sexual contacts of the infected patients or to children who are not already infected perinatally.[15-19] However, if casual person-to-person transmission of HTLV-III/LAV infection does exist, it should theoretically be greatest among young children. This theoretical transmission would most likely involve exposure of open skin lesions or mucous membranes to blood and possibly other body fluids of an infected person. We emphasize that there is no evidence of this type of transmission occurring in any setting at this time.

GENERAL RECOMMENDATIONS

Education

1. **Risk-Reduction Education.** All sexually active homosexual, bisexual, and heterosexual adults with multiple sexual partners since 1979 should be aware that they are potentially at risk of HTLV-III/LAV infection, and sexually active women with multiple sexual partners since 1979 should understand that, if they have been infected, they are at risk of transmitting HTLV-III/LAV perinatally. To this end, widespread health education campaigns should address the risk of infection and the ways to prevent sexual transmission among heterosexuals and, more specifically, to women of child-bearing age. Additionally, women in recognized risk groups (Table 1) should be the target of more intensified educational campaigns and, if indicated, special educational programs to decrease their ongoing risk of parenterally or sexually acquiring HTLV-III/LAV infection, such as referral for substance abuse or sexual risk reduction counseling. These campaigns should be culturally and linguistically appropriate for these risk groups.

2. **Provider Education.** In order to provide a high standard of care for HTLV-III/LAV-infected women, infants, and children, obstetricians, pediatricians, foster parents and agencies, and other providers need to be educated about the virus, its modes of transmission, its prevention, and the special issues of confidentiality and counseling surrounding the infection. Focus should be placed on educating and training those providers serving patients at highest risk of infection. We recommend that providers assess each patient's history of potential exposure to HTLV-III/LAV and not assume that membership in a risk group implies de facto infection and, conversely, that non-membership implies non-infection.

Laboratory

We recommend that more than one method of anti-HTLV-III antibody determination be used for testing pregnant women, women in risk groups, and children of women in risk groups for HTLV-III/LAV infection. Such methods include enzyme-linked immunosorbent assay (ELISA), indirect fluorescent antibody, and Western blot. Because of the complexity of prenatal testing, especially that involving intravenous-drug-using women, laboratory testing should be done in a single reliable and experienced facility. Submission of specimens identified only by code number to this laboratory will greatly decrease the chances of inadvertant disclosure.

Pre-Conception Recommendations

Whenever possible, women infected with HTLV-III/LAV should be confidentially identified and educated about the risks of perinatal transmission. Infected women should be advised to postpone pregnancy until more is known about the specific risks of perinatal transmission. Detailed contraceptive counseling should be offered to these women. Infected women should also be counseled to avoid unsafe sexual practices. Regardless of other contraceptive methods used, they should use barrier methods of contraception (e.g., condom or condom plus a diaphragm with a nonoxynol-9-containing spermicide) during intercourse in order to diminish the chances of transmitting HTLV-III/LAV to their sexual partners.

We recommend that women who believe themselves to be at high risk for HTLV-III/LAV infection (Table 1) be confidentially or anonymously tested for anti-HTLV-III antibody if they are planning to become pregnant. Testing can be offered through private physicians, alternate test sites, or through clinics, especially those used by women in risk groups, such as family planning clinics, drug treatment programs, and sexually transmitted disease clinics. Testing of these women, although strongly recommended, must be voluntary and confidential. We do not recommend that women who are not in risk groups be tested at this time. However, because of possible sexual contact with men in high-incidence groups, it may be prudent for women with multiple sexual partners in areas with high incidence of AIDS to consider themselves at risk and obtain pre-conception counseling and testing if indicated. Regardless of test results, women and their children should continue to have access to all health and social services for which they are eligible.

MATERNAL RECOMMENDATIONS

Identification of Infected Pregnant Women

Routine histories taken at clinical facilities serving women potentially at high risk for HTLV-III/LAV infection should include confidential questions designed to elucidate their risk of infection. Such clinics include physicians' offices, family planning clinics, sexually transmitted disease clinics, drug treatment clinics, WIC clinics, and prenatal clinics. Written and/or audiovisual materials regarding HTLV-III/LAV infection should be available at all sites where these women are seen.

We recommend that women in risk groups be educated about HTLV-III/LAV infection and that women determined to be at risk be tested at the time they present for prenatal care. Such testing must be voluntary and confidential. We do not recommend routine testing of all pregnant women. High risk women who are seronegative in the first or second trimester should be retested in the late third trimester to rule-out intercurrent HTLV-III/LAV infection. Because quality obstetrical care requires that the obstetrical provider know if an individual patient is infected, we recommend that, whenever possible, the test be obtained through the provider. However, before such testing occurs, each provider should institute procedures which guarantee patient confidentiality. A release of information form authorizing the newborn's medical provider access to the mother's test result should also be obtained at this time. Sample consent and release of information forms are included in Appendices I and II. Because of the unique potential for exposure of health care workers to large amounts of potentially infectious blood and amniotic fluid during the course of labor and delivery, we recommend that labor and delivery personnel be notified of the need for appropriate infection control procedures on a strictly controlled basis. Ideally, this information should be transmitted directly to labor and delivery personnel and through a mechanism other than the permanent medical record.

Care of Infected Pregnant Women

These recommendations apply specifically to women who are known to be infected. Guidelines for women at high risk of infection who have not been tested for HTLV-III/LAV infection are found under "Special Considerations" below.

1. **Prenatal Care.** We recommend that any seropositive woman be retested using two different anti-HTLV-III antibody determinations to insure accuracy. We recommend that women confirmed to be seropositive be carefully counseled regarding the risk of perinatal HTLV-III/LAV infection and the options open to them.

Such options include continuation of the pregnancy or termination of pregnancy if early enough in gestation. Infected women should also be specifically counseled to postpone subsequent pregnancies until more is known about perinatal transmission of the virus. They should be medically evaluated to rule-out any incipient opportunistic infections or malignancies. Specifically, the possibility of infection with *Mycobacterium tuberculosis* should be evaluated by chest x-ray and PPD, and chronic infection with hepatitis B virus, cytomegalovirus, and Herpes simplex virus should be excluded. Teratogenic drugs, including trimethoprim and most antivirals, should be avoided except in the face of life-threatening maternal illness.

2. **Intrapartum Care.** We recommend that hospitals review their procedures for infection control during the intrapartum period and that hospital personnel exercise caution when dealing with any potentially infectious body fluid. For HTLV-III/LAV these fluids include blood of either maternal or fetal origin, amniotic fluid, and the placenta and membranes. Grossly contaminated linens and disposables, as well as blood and amniotic fluid specimens, should be handled according to the hospital infection control procedures. The choice of location for delivery (delivery room versus labor room) may be dictated by circumstance, but consideration should be given to a labor room delivery to minimize the need for disinfection of two locations. All personnel expected to have direct contact with an infected mother or newborn during delivery should wear gloves and gowns. Those exposed to the potential of a splash of infectious materials should strongly consider wearing a mask and protective eyewear during the delivery itself. Disposal of all materials should follow hospital infection control procedures. The labor room, delivery room, and all instruments should be disinfected with a 1:10 sodium hypochlorite solution. The placenta of a seropositive or of a high risk woman of unkown status should be labeled with "H/A Precautions" or the equivalent prior to routing for pathologic examination or disposal.

3. **Postpartum Care.** In the postpartum period, regular hospital infection control procedures for HTLV-III/LAV infection should be followed. Isolation of asymptomatic seropositive women is not recommended. Mothers should be given full access to their infants unless they have untreated pulmonary tuberculosis. Until more is known about the potential transmission of virus in breast milk, infants of mothers known to be infected should not be breast fed. However, as the benefits of breast feeding in all likelihood virus, we do not recommend that breast feeding be restricted unless the mother is known to be infected. Because the potential for exposure to large amounts of infectious material decreases markedly after delivery, information regarding the woman's antibody status should not be transmitted beyond the labor and delivery area, including to social work, law enforcement, or correctional personnel.

Special Considerations

1. **Women at High Risk of Infection who are not Screened.** We recommend that women at high risk of HTLV-III/LAV infection who have not been tested during pregnancy be presumed to be positive for purposes of intrapartum infection control procedures.

2. **Intravenous-Drug-Using Mothers.** In order to prevent further parenteral transmission of HTLV-III/LAV through needle sharing and further perinatal transmission, we recommend that women in this risk group be specially targeted for substance abuse treatment and risk reduction education.

INFANT AND PRE-SCHOOL-AGED CHILD RECOMMENDATIONS

Identification of Exposed Infants

We recommend that identification of HTLV-III/LAV-exposed infants begin *in utero*. If women in high incidence groups are not tested during pregnancy, we recommend that for medical reasons their infants be tested as early as possible (e.g., cord blood) and definitely before two months of age. Such testing should be done confidentially and with the voluntary consent of the child's parent or guardian.

Identification of Infected Infants

1. **Infants of Seropositive Mothers.** Infants born to mothers who are known to have been infected during pregnancy should be retested for anti-HTLV-III antibody at approximately one year of age when passively acquired maternal antibody has disappeared. Infants presenting before one year of age with symptoms suggestive of HTLV-III/LAV infection should be retested at that time. If an IgM-specific anti-HTLV-III antibody test or other method of early diagnosis becomes available, these infants should be tested for HTLV-III/LAV infection at birth.

2. **Infants and Children of High-Risk Mothers with Unknown Serologic Status.** Infants born to mothers at high-risk of HTLV-III/LAV infection whose prenatal anti-HTLV-III antibody status is unknown should be tested before two months of age for exposure to HTLV-III/LAV and retested at one year of age or earlier if clinically indicated. Older children who were born on or after January 1, 1979, and whose mothers were at risk of HTLV-III/LAV infection should be tested only (a) if they have not completed a primary series of oral polio vaccine and have not received a measles-mumps-rubella vaccination or (b) if clinically indicated. Because of potential complications of live virus vaccines, we recommend that older high-risk children be tested for HTLV-III/LAV exposure or infection prior to receiving live virus vaccines. In the event that the parent or guardian refuses testing, the infant or child should not receive live virus vaccines.

3. **Infants and Children at Risk for Parenterally Acquired Infection.** Infants and children at risk for parenterally-acquired HTLV-III/LAV infection should be tested only (a) if they received blood or blood products from a donor identified as HTLV-III/LAV-infected and will receive live virus vaccines ; (b) if they were transfused with non-heat-treated Factor VIII and will receive live virus vaccines; or (c) if clinically indicated.

4. **Infants and Children of Non-High-Risk Mothers.** Infants and children born to mothers not at high risk of HTLV-III/LAV infection and not at risk for parenterally acquired HTLV-III/LAV infection should not be tested.

Care of Exposed and Infected Infants and Children

1. **Nursery and In-Hospital Care.** Regular hospital infection control procedures for HTLV-III/LAV infection and regular hospital procedures for inpatient care of immunosuppressed patients should be followed in the nursery and during subsequent inpatient admissions. In order to prevent potential sources of infection, circumcision of exposed male infants should be strongly discouraged and only done with informed consent. Umbilical stumps should be meticulously cleaned daily until they are evulsed.

2. **Routine Home Care.** Caregivers who are exposed to the body fluids and excrement of exposed infants and infected children should be aware of the potential for infection and the modes of HTLV-III/LAV transmission. Good handwashing after exposure to body fluids and excrement should be observed and any open lesions, either on caregivers' hands or on children, should be covered.

3. **Medical Care.** Exposed infants who remain anti-HTLV-III positive beyond age 1 year or who have documented positive HTLV-III/LAV cultures at any age should be considered at risk for the development of AIDS or ARC and, therefore, potentially immunodeficient. Infants and children either at risk for the development of AIDS or ARC or who have clinical AIDS or ARC should be assumed to have a secondary combined immunodeficiency, be followed closely for problems with growth and development, and be given prompt and aggressive therapy for infections and exposure to potentially lethal infections, such as varicella and measles.

Exposed infants and infected children should not receive live virus vaccines or BCG until more is known about vaccination of HTLV-III/LAV-infected persons. Inactivated vaccines, including *Haemophilus influenzae* type b and pertussis vaccines and diphtheria and tetanus toxoids, are not contraindicated and should be given as regularly scheduled. Inactivated polio vaccine should be substituted for oral polio vaccine and be given in conjunction with diphtheria and tetanus toxoids and pertussis vaccine at 2, 4, 6, and 18 months and 4-6 years of age.

Measles, mumps, and rubella vaccine should not be administered to these children at the present time.

Infants or children with clinical AIDS or ARC should be evaluated and cared for as if they have combined immunodeficiency disease. Because these children potentially have a significant cellular immunodeficiency, all blood products should be irradiated to avoid graft versus host disease. Until more is known about the natural history of disease in infants who remain anti-HTLV-III positive beyond one year of age, the immune status of these children should be sequentially evaluated with the consultation of a pediatric immunologist. The increased risk of *Pneumocystis carinii* pneumonia in these children may be modified by the use of prophylactic trimethoprim-sulfamethoxazole. As these children do not make normal specific antibodies to new antigens, their increased risk of infection with bacterial agents may be altered by monthly administration of immune serum globulin, either intramuscularly or intravenously.

Special Considerations

1. **Foster Care.** In each decision involving foster care placement, a mother's history of potential exposure to HTLV-III/LAV infection should be individually assessed to determine if she and her child are truly at risk of infection. These decisions can be made in consultation with a perinatal coordinator within DPH or, if necessary, with the Perinatal and Pediatric AIDS Advisory Committee. For the purposes of foster care decisions, the Committee will also include consumer advocates representative of ethnic and socio-economic populations at high risk for perinatally transmitted infection.

If a child whose mother has been tested for HTLV-III/LAV infection comes to foster care, we recommend that the DSS caseworker assigned to the case request that the mother's obstetrical provider release the results of her test to the perinatal coordinator with the mother's consent. A sample release of information form is included in Appendix II. Based on the results of these tests the perinatal coordinator will specify if the infant will need medical foster care placement or routine foster care placement. Medical placement will be required for infants of mothers with a positive anti-HTLV-III antibody test and will entail review of the placement decision by the Perinatal and Pediatric AIDS Advisory Committee. Routine placement will require that the mother be seronegative. The perinatal coordinator will also inform the caseworker assigned to follow the child of the reasons for medical placement and will also be responsible, in conjunction with the caseworker, for informing the foster family and the child's pediatrician of the reasons for medical placement. Additional releases of information will be required for each of these subsequent disclosures.

Children less than three years old currently in foster care and children entering foster care in the future whose mothers were not tested for HTLV-III/LAV infection prenatally should be tested for HTLV-III/LAV infection only if their mothers have been determined to be at risk of infection. Testing in this setting is indicated on medical grounds alone and should be done with the consent of the mother. A sample consent form is included in Appendix III. If the mother refuses to consent to testing or refuses to release the results of her test, we recommend that the case be reviewed by the Perinatal and Pediatric AIDS Advisory Committee and, if indicated, confidential testing of the child and release of the test results be ordered as part of dependency proceedings. Once results of the test are available they will be released by the child's provider to the perinatal coordinator in the case of voluntary testing or reported directly by the laboratory to the perinatal coordinator in the case of court-ordered testing. The perinatal coordinator will then indicate whether the child is in need of medical placement or routine placement. If the child is in need of medical placement, the perinatal coordinator will follow procedures as outlined above. If, for whatever reason, the child is not tested, the mother's exposure history will be reviewed and appropriate placement recommended by the Perinatal and Pediatric AIDS Advisory Committee.

Children in foster care three years old and older, born after January 1, 1979, and born to a mother determined to be at risk of HTLV-III/LAV infection should be tested only if they have significant neurodevelopmental delay and lack control of their body secretions or display aggressive behavior, such as biting, or who have uncoverable, oozing lesions. Such testing should occur only after careful medical review by the Perinatal and Pediatric AIDS Advisory Committee to determine if such behaviors truly increase the theoretical risk of casual HTLV-III/LAV transmission. Again, the consent of the child's mother should be obtained for testing and release of information, or, if consent is not available, testing and release of information should be ordered by the court if indicated.

Under Section 199.21 of the Health and Safety Code of the State of California (AB 403) (Attachment III), it is unlawful to disclose the results of a blood test to detect antibodies to the probable causative agent of AIDS to any third party except pursuant to a written authorization of the person who is tested. Therefore, if written releases of information are unavailable, specific waivers will need to be obtained so that prenatal testing results can be made available by the mother's obstetric care provider to the perinatal coordinator and so that the perinatal coordinator can make either prenatal or postnatal screening results available to the DSS caseworker, the child's foster family, and the child's pediatrician. Additionally, under Section 199.22, no person shall test a person's blood for evidence of antibodies to the probable causative agent of AIDS without the written consent of the subject of the test. We feel that all prenatal testing should be done on a voluntary basis and that the mother should freely consent both to being tested and to release the test results in order to assure better medical care of her children. However, in the event that a mother determined to be at risk of infection has not been tested prenatally, refuses to be tested prenatally, or refuses to consent to release the results of her prenatal test, as it is our opinion that testing of high-risk children for HTLV-III/LAV infection is medically indicated, we recommend that, if these children are to be placed in foster homes, such testing be obtained and, if necessary, be specifically ordered by the court having jurisdiction over the child. However, prior to any court-ordered testing, the case must be reviewed by the Perinatal and Pediatric AIDS Advisory Committee to determine if testing is indeed indicated.

2. **Adoption.** We recommend that infants and children (a) whose mothers were at high risk of HTLV-III/LAV infection, (b) who were born on or after January 1, 1979, and (c) who have not been previously tested be tested for HTLV-III/LAV infection prior to placement. We recommend that the HTLV-III/LAV status of all children at high risk of infection be made available to adopting parents prior to final placement so that they can consider the possible social and psychological effects on their families.

CONCLUSIONS

We reemphasize that these are interim guidelines which will need to be reviewed as more information becomes available on perinatal transmission, the natural history of HTLV-III/LAV infection in pregnancy and childhood, and household transmission and also as vaccine and definitive antiviral therapy become available. Finally, it should be clearly stated that all evidence suggests that there is no risk for casual transmission of HTLV-III/LAV and that the primary intent of these guidelines is to assure appropriate medical care for infected pregnant women, infants, and children.

TABLE 1. Groups in Which HTLV-III/LAV Infection Has Been Reported, Females

Mode of Transmission	Group
Sexual	Sexual contacts of AIDS patients or men in risk groups*
	Artifically inseminated women (donor insemination) between January 1, 1979, and June 1, 1985
Parenteral	Intravenous drug users
	Recipients of blood or blood products between January 1, 1979, and June 1, 1985
Either	Mothers of perinatally infected children

* Women with multiple sexual partners in areas with high incidence of AIDS should possibly consider themselves in this category.

References

1. CDC. Education and foster care of children infected with human T-lymphotropic virus-type III/lymphadenopathy-associated virus. MMWR 1985; 34:517-21.

2. CDC. Recommendations for assisting in the prevention of perinatal transmission of human T-lymphotropic virus-type III/lymphadenopathy-associated virus and acquired immunodeficiency syndrome. MMWR 1985; 34:721-6, 731-2.

3. CDC. Unexplained immunodeficiency and opportunistic infections in infants - New York, New Jersey, California. MMWR 1982; 31:665-7.

4. Cowan MJ, Hellman D, Chudwin DI, et al. Maternal transmission of acquired immune deficiency syndrome. Pediatrics 1984; 73:382-6.

5. Joncas JH, Delage G, Chad Z, et al. Acquired (or congenital) immunodeficiency syndrome in infants born of Haitian mothers [letter]. N Engl J Med 1983; 308:842.

6. Lapointe N, Michaud J, Pekovic D, et al. Transplacental transmission of HTLV-III virus. N Engl J Med 1985; 312:1325-6.

7. Oleske J, Minnefor A, Cooper R Jr, et al. Immune deficiency syndrome in children. JAMA 1983; 249:2345-9.

8. Rubenstein A, Sicklic M, Gupta A, et al. Acquired immunodeficiency syndrome with reversed T4/T8 ratios in infants born to promiscuous and drug-addicted mothers. JAMA 1983; 249:2350-6.

9. Scott GB, Buck BE, Letterman JG, et al. Acquired immunodeficiency syndrome in infants. N Engl J Med 1984; 310: 76-81.

10. Scott GB, Fischl MA, Klimas N, et al. Mothers of infants with acquired immunodeficiency syndrome (AIDS): evidence for both symptomatic and asymptomatic carriers. JAMA 1985; 253:363-6.

11. Thomas PA, Jaffe HW, Spira TJ, et al. Unexplained immunodeficiency in children. JAMA 1984; 252:639-44.

12. Ziegler JB, Cooper DA, Johnson RO, et al. Postnatal transmission of AIDS-associated retrovirus from mother to infant. Lancet 1985; 1:896-8.

13. Rogers MF. AIDS in children: a review of the clinical, epidemiologic, and public health aspects. Pediatr Infect Dis 1985; 4:230-6.

14. CDC. Apparent transmission of human T-lymphotropic virus-type III/lymphadenopathy-associated virus from a child to a mother providing health care. MMWR 1986; 35:76-9.

15. Fischl MA, Dickinson G, Scott G, et al. Evaluation of household contacts of adult patients with the acquired immunodeficiency syndrome. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 16, 1985.

16. Friedland GH, Saltzman BR, Rogers MF, et al. Lack of transmission of HTLV-III infection to household contacts of patients with AIDS or AIDS-related complex with oral candidiasis. N Engl J Med 1986; 314:344-9.

17. Kaplan JE, Oleske JM, Getchell JP, et al. Evidence against transmission of HTLV-III/LAV in families of children with AIDS. Pediatr Infect Dis 1985; 4:468-71.

18. Lewin EB, Zack R, Ayodele A. Communicability of AIDS in a foster care setting. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 16, 1985.

19. Thomas PA, Lubin K, Enlow RW, et al. Comparison of HTLV-III serology, T-cell levels, and general health status of children whose mothers have AIDS with children of healthy inner city mothers in New York. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 16, 1985.

APPENDIX I

MODEL

INFORMED CONSENT TO DO TEST FOR AIDS VIRUS (HTLV-III/LAV) ANTIBODY

IMPORTANT INFORMATION REGARDING THIS TEST

The AIDS virus (HTLV-III/LAV) antibody test detects the presence of antibodies, naturally occurring substances in the blood produced by the body following infection with the AIDS virus, by using a simple blood test. This is not a test for AIDS. The test does not tell you if you have AIDS or an AIDS-related condition (ARC); it does show whether you have been infected with the virus that can cause AIDS. For further information regarding AIDS or the AIDS virus antibody test, consult your physician or call the San Francisco AIDS Foundation Hotline (415-863-AIDS).

I understand that this test result will be part of my medical record and my baby's medical record. I have been informed about the AIDS virus (HTLV-III/LAV) antibody test (see reverse). I have had a chance to ask questions which were answered to my satisfaction. I believe that I understand the benefits and risks of the test.

Date: _______ 19___ ________________________________
(Patient's Signature)

____
(Patient's Printed Name)

____
(Witness)

HTLV-III ANTIBODY TEST - LIMITATIONS AND IMPLICATIONS

A. This test will not tell you:

- if your child has AIDS or ARC (AIDS related condition);
- if your child will develop AIDS or ARC;
- if your child is immune to AIDS or ARC;
- if your child is healthy.

B. A negative test result indicates that the antibody has not been found in your child's blood. If your child tests negative, there are three possible explanations:
- your child has not been infected with the virus; or
- your child has been exposed to the virus but has not become infected; or
- your child has been infected by the virus but has not yet produced antibodies.

Research indicates most people produce antibodies within 2-8 weeks after infection. Some people will not produce antibodies for six months or more. A very small number of people will never produce antibodies.

C. A positive test result indicates that your child has probably been infected with the AIDS virus, and his or her body has produced antibodies. Researchers have shown that most people with AIDS antibodies have active virus in their bodies. A positive result does not mean:
- that your child has AIDS or ARC;
- that your child will necessarily get AIDS or ARC;
- that your child is immune to AIDS.

D. Not everyone infected with the virus will develop AIDS.

1. The majority of infected children will develop antibodies to the virus yet remain healthy. They will display none of the symptoms of AIDS.

2. A smaller group of children who also have antibodies will develop some of the symptoms of AIDS. These children are diagnosed as having ARC (AIDS-related condition).

3. An unknown percentage of infected, antibody-positive children will develop AIDS. A diagnosis of AIDS is made only after finding specific life-threatening infections or malignancies that do not normally occur in healthy children.

E. NOTE ABOUT CONFIDENTIALITY - Parents of children taking the test should be aware that there may be some risk associated with letting others know about their child's test results. While using test results as grounds for discrimination in insurance or employment is prohibited by California law, the burden of proof is on the person discriminated against.

APPENDIX II

MODEL

AUTHORIZATION TO RELEASE THE RESULTS OF A BLOOD TEST TO DETECT ANTIBODIES TO THE AIDS RELATED VIRUS (HTLV-III)

A. EXPLANATION:

Permission to release the results of your blood test to detect antibodies to the AIDS related virus (HTLV-III) is being asked of you to fulfill the terms of the Confidentiality of Medical Information Act, Civil Code Section 56 et seq. and Health and Safety Code, Section 199.21 (f,g,h).

Written permission must be given for each separate release of AIDS antibody test results by a person or institution who did the test. Release of your test results without your consent is punishable by fine (Health & Safety Code, Section 199.21 (a,b,c,d,e)).

B. AUTHORIZATION:

I hereby authorize ______________________________
(Name of person or institution)

to release to ______________________________
(Name of the person who is to receive the results)

the results of blood tests to detect antibodies to the AIDS virus (HTLV-III/LAV).

C. USES:

The results of the test cannot be used to deny insurance or employment. The information will be used only for the medical care [and foster-care placement]* of your baby.

D. DURATION:

This authorization shall be effective immediately and shall remain in effect indefinitely or until ____________ 19 ___.

E. RESTRICTIONS:

I understand that the requester may not further use or release my test results unless another authorization is obtained from me.

F. ADDITIONAL COPY:

I further understand that I have a right to receive a copy of this authorization upon my request.

Date: ____________ 19____ ______________________________
(Patient's Signature)

____
(Patient's Printed Name)

Original to Medical Record
Copy to Patient
Copy to person who is to receive the results.

APPENDIX III

MODEL

INFORMED CONSENT TO DO TEST FOR AIDS VIRUS (HTLV-III/LAV) ANTIBODY

IMPORTANT INFORMATION REGARDING THIS TEST

The AIDS virus (HTLV III/LAV) antibody test detects the presence of antibodies, naturally occurring substances in the blood produced by the body following infection with the AIDS virus, by using a simple blood test. This is not a test for AIDS. The test does not tell you if your child has AIDS or an AIDS-related condition (ARC); it does show whether your child has been infected with the virus that can cause AIDS. For further information regarding AIDS or AIDS virus antibody test, consult your child's physician or call the San Francisco AIDS Foundation Hotline (415-863-AIDS).

I understand that this test result will be part of my child's medical record. I have been informed about the AIDS virus (HTLV-III/LAV) antibody test (see reverse). I have had a chance to ask questions which were answered to my satisfaction. I believe that I understand the benefits and risks of the test.

Date: ________ 19___ ______________________________
(Parent's or Guardian's Signature)

____
(Patient's Printed Name)

____
(Witness)

HTLV-III ANTIBODY TEST -- LIMITATIONS AND IMPLICATIONS

A. This test will not tell you:
- if you have AIDS or ARC (AIDS related condition);
- if you will develop AIDS or ARC;
- if you are immune to AIDS or ARC;
- if you are healthy.

B. A negative test result indicates that the antibody has not been found in your blood. If you test negative, there are three possible explanations:
- you have not been infected with the virus; or
- you have had contact with the virus but have not become infected; or
- you have been infected by the virus but have not yet produced antibodies.

Research indicates most people produce antibodies within 2-8 weeks after infection. Some people will not produce antibodies for six months or more. A very small number of people will never produce antibodies.

A negative result does not mean:
- that you are immune to the virus;
- that you have not been infected with the virus. You may have been infected and have not yet produced antibodies.

C. A positive test result indicates that you have probably been infected with the AIDS virus and your body has produced antibodies. Researchers have shown that most people with AIDS antibodies have active virus in their bodies. You may therefore assume you are contagious and capable of passing the virus on to others including your baby. A positive result does not mean:
- that you have AIDS or ARC;
- that you will necessarily get AIDS or ARC;
- that you are immune to AIDS.

D. Not everyone infected with the virus will develop AIDS.
1. The majority of infected people will develop antibodies to the virus yet remain healthy. They will display none of the symptoms of AIDS.
2. A smaller group of people who also have antibodies will develop some of the symptoms of AIDS. These people are diagnosed as having ARC (AIDS-related condition).
3. An unknown percentage of infected people will develop AIDS. A diagnosis of AIDS is made only after finding specific life-threatening infections or malignancies that do not normally occur in healthy people.

E. NOTE ABOUT CONFIDENTIALITY - People taking the test should be aware that there may be some risk associated with letting others know about their test results. While using test results as grounds for discrimination in insurance or employment is prohibited by California law, the burden of proof is on the person discriminated against. There are benefits associated with telling your physician, dentist, and sexual partners. You should ascertain first, however, what they will do with the information and who they will share it with.

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Current Trends

Education and Foster Care of Children Infected with Human T-Lymphotropic Virus Type III/ Lymphadenopathy-Associated Virus

The information and recommendations contained in this document were developed and compiled by CDC in consultation with individuals appointed by their organizations to represent the Conference of State and Territorial Epidemiologists, the Association of State and Territorial Health Officers, the National Association of County Health Officers, the Division of Maternal and Child Health (Health Resources and Services Administration), the National Association for Elementary School Principals, the National Association of State School Nurse Consultants, the National Congress of Parents and Teachers, and the Children's Aid Society. The consultants also included the mother of a child with acquired immunodeficiency syndrome (AIDS), a legal advisor to a state education department, and several pediatricians who are experts in the field of pediatric AIDS. This document is made available to assist state and local health and education departments in developing guidelines for their particular situations and locations.

These recommendations apply to all children known to be infected with human T-lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV). This includes children with AIDS as defined for reporting purposes (Table 1); children who are diagnosed by their physicians as having an illness due to infection with HTLV-III/LAV but who do not meet the case definition; and children who are asymptomatic but have virologic or serologic evidence of infection with HTLV-III/LAV. These recommendations do not apply to siblings of infected children unless they are also infected.

BACKGROUND

The Scope of the Problem. As of August 20, 1985, 183 of the 12,599 reported cases of AIDS in the United States were among children under 18 years of age. This number is expected to double in the next year. Children with AIDS have been reported from 23 states, the District of Columbia, and Puerto Rico, with 75% residing in New York, California, Florida, and New Jersey.

The 183 AIDS patients reported to CDC represent only the most severe form of HTLV-III/LAV infection, i.e., those children who develop opportunistic infections or malignancies (Table 1). As in adults with HTLV-III/LAV infection, many infected children may have milder illness or may be asymptomatic.

Legal Issues. Among the legal issues to be considered in forming guidelines for the education and foster care of HTLV-III/LAV-infected children are the civil rights aspects of public school attendance, the protections for handicapped children under 20 U.S.C. 1401 et seq. and 29 U.S.C. 794, the confidentiality of a student's school record under state laws and under 20 U.S.C. 1232g, and employee right-to-know statutes for public employees in some states.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES / PUBLIC HEALTH SERVICE

HTLV-III/LAV — Continued

TABLE 1. Provisional case definition for acquired immunodeficiency syndrome (AIDS) surveillance of children

For the limited purposes of epidemiologic surveillance, CDC defines a case of pediatric acquired immunodeficiency syndrome (AIDS) as a child who has had:

1. A reliably diagnosed disease at least moderately indicative of underlying cellular immune deficiency; and
2. No known cause of underlying cellular immunodeficiency or any other reduced resistance reported to be associated with that disease.

The diseases accepted as sufficiently indicative of underlying cellular immunodeficiency are the same as those used in defining AIDS in adults. In the absence of these opportunistic diseases, a histologically confirmed diagnosis of chronic lymphoid interstitial pneumonitis will be considered indicative of AIDS unless test(s) for HTLV-III/LAV are negative. Congenital infections, e.g., toxoplasmosis or herpes simplex virus infection in the first month after birth or cytomegalovirus infection in the first 6 months after birth must be excluded.

Specific conditions that must be excluded in a child are:

1. Primary immunodeficiency diseases – severe combined immunodeficiency, DiGeorge syndrome, Wiskott-Aldrich syndrome, ataxia-telangiectasia, graft versus host disease, neutropenia, neutrophil function abnormality, agammaglobulinemia, or hypogammaglobulinemia with raised IgM.
2. Secondary immunodeficiency associated with immunosuppressive therapy, lymphoreticular malignancy, or starvation.

Confidentiality Issues. The diagnosis of AIDS or associated illnesses evokes much fear from others in contact with the patient and may evoke suspicion of life styles that may not be acceptable to some persons. Parents of HTLV-III/LAV-infected children should be aware of the potential for social isolation should the child's condition become known to others in the care or educational setting. School, day-care, and social service personnel and others involved in educating and caring for these children should be sensitive to the need for confidentiality and the right to privacy in these cases.

ASSESSMENT OF RISKS

Risk Factors for Acquiring HTLV-III/LAV Infection and Transmission. In adults and adolescents, HTLV-III/LAV is transmitted primarily through sexual contact (homosexual or heterosexual) and through parenteral exposure to infected blood or blood products. HTLV-III/LAV has been isolated from blood, semen, saliva, and tears but transmission has not been documented from saliva and tears. Adults at increased risk for acquiring HTLV-III/LAV include homosexual/bisexual men, intravenous drug abusers, persons transfused with contaminated blood or blood products, and sexual contacts of persons with HTLV-III/LAV infection or in groups at increased risk for infection.

The majority of infected children acquire the virus from their infected mothers in the perinatal period (*1-4*). In utero or intrapartum transmission are likely, and one child reported from Australia apparently acquired the virus postnatally, possibly from ingestion of breast milk (*5*). Children may also become infected through transfusion of blood or blood products that contain the virus. Seventy percent of the pediatric cases reported to CDC occurred among children whose parent had AIDS or was a member of a group at increased risk of acquiring HTLV-III/LAV infection; 20% of the cases occurred among children who had received blood or blood products; and for 10%, investigations are incomplete.

HTLV III/LAV – Continued

Risk of Transmission in the School, Day-Care or Foster-Care Setting. None of the identified cases of HTLV-III/LAV infection in the United States are known to have been transmitted in the school, day-care, or foster-care setting or through other casual person-to-person contact. Other than the sexual partners of HTLV-III/LAV-infected patients and infants born to infected mothers, none of the family members of the over 12,000 AIDS patients reported to CDC have been reported to have AIDS. Six studies of family members of patients with HTLV-III/LAV infection have failed to demonstrate HTLV-III/LAV transmission to adults who were not sexual contacts of the infected patients or to older children who were not likely at risk from perinatal transmission (6-11).

Based on current evidence, casual person-to-person contact as would occur among schoolchildren appears to pose no risk. However, studies of the risk of transmission through contact between younger children and neurologically handicapped children who lack control of their body secretions are very limited. Based on experience with other communicable diseases, a theoretical potential for transmission would be greatest among these children. It should be emphasized that any theoretical transmission would most likely involve exposure of open skin lesions or mucous membranes to blood and possibly other body fluids of an infected person.

Risks to the Child with HTLV-III/LAV Infection. HTLV-III/LAV infection may result in immunodeficiency. Such children may have a greater risk of encountering infectious agents in a school or day-care setting than at home. Foster homes with multiple children may also increase the risk. In addition, younger children and neurologically handicapped children who may display behaviors such as mouthing of toys would be expected to be at greater risk for acquiring infections. Immunodepressed children are also at greater risk of suffering severe complications from such infections as chickenpox, cytomegalovirus, tuberculosis, herpes simplex, and measles. Assessment of the risk to the immunodepressed child is best made by the child's physician who is aware of the child's immune status. The risk of acquiring some infections, such as chickenpox, may be reduced by prompt use of specific immune globulin following a known exposure.

RECOMMENDATIONS

1. Decisions regarding the type of educational and care setting for HTLV-III/LAV-infected children should be based on the behavior, neurologic development, and physical condition of the child and the expected type of interaction with others in that setting. These decisions are best made using the team approach including the child's physician, public health personnel, the child's parent or guardian, and personnel associated with the proposed care or educational setting. In each case, risks and benefits to both the infected child and to others in the setting should be weighed.
2. For most infected school-aged children, the benefits of an unrestricted setting would outweigh the risks of their acquiring potentially harmful infections in the setting and the apparent nonexistent risk of transmission of HTLV-III/LAV. These children should be allowed to attend school and after-school day-care and to be placed in a foster home in an unrestricted setting.
3. For the infected preschool-aged child and for some neurologically handicapped children who lack control of their body secretions or who display behavior, such as biting, and those children who have uncoverable, oozing lesions, a more restricted environment is advisable until more is known about transmission in these settings. Children infected with HTLV-III/LAV should be cared for and educated in settings that minimize exposure of other children to blood or body fluids.

HTLV III/LAV – Continued

4. Care involving exposure to the infected child's body fluids and excrement, such as feeding and diaper changing, should be performed by persons who are aware of the child's HTLV-III/LAV infection and the modes of possible transmission. In any setting involving an HTLV-III/LAV-infected person, good handwashing after exposure to blood and body fluids and before caring for another child should be observed, and gloves should be worn if open lesions are present on the caretaker's hands. Any open lesions on the infected person should also be covered.
5. Because other infections in addition to HTLV-III/LAV can be present in blood or body fluids, all schools and day-care facilities, regardless of whether children with HTLV-III/LAV infection are attending, should adopt routine procedures for handling blood or body fluids. Soiled surfaces should be promptly cleaned with disinfectants, such as household bleach (diluted 1 part bleach to 10 parts water). Disposable towels or tissues should be used whenever possible, and mops should be rinsed in the disinfectant. Those who are cleaning should avoid exposure of open skin lesions or mucous membranes to the blood or body fluids.
6. The hygienic practices of children with HTLV-III/LAV infection may improve as the child matures. Alternatively, the hygienic practices may deteriorate if the child's condition worsens. Evaluation to assess the need for a restricted environment should be performed regularly.
7. Physicians caring for children born to mothers with AIDS or at increased risk of acquiring HTLV-III/LAV infection should consider testing the children for evidence of HTLV-III/LAV infection for medical reasons. For example, vaccination of infected children with live virus vaccines, such as the measles-mumps-rubella vaccine (MMR), may be hazardous. These children also need to be followed closely for problems with growth and development and given prompt and aggressive therapy for infections and exposure to potentially lethal infections, such as varicella. In the event that an antiviral agent or other therapy for HTLV-III/LAV infection becomes available, these children should be considered for such therapy. Knowledge that a child is infected will allow parents and other caretakers to take precautions when exposed to the blood and body fluids of the child.
8. Adoption and foster-care agencies should consider adding HTLV-III/LAV screening to their routine medical evaluations of children at increased risk of infection before placement in the foster or adoptive home, since these parents must make decisions regarding the medical care of the child and must consider the possible social and psychological effects on their families.
9. Mandatory screening as a condition for school entry is not warranted based on available data.
10. Persons involved in the care and education of HTLV-III/LAV-infected children should respect the child's right to privacy, including maintaining confidential records. The number of personnel who are aware of the child's condition should be kept at a minimum needed to assure proper care of the child and to detect situations where the potential for transmission may increase (e.g., bleeding injury).
11. All educational and public health departments, regardless of whether HTLV-III/LAV-infected children are involved, are strongly encouraged to inform parents, children, and educators regarding HTLV-III/LAV and its transmission. Such education would greatly assist efforts to provide the best care and education for infected children while minimizing the risk of transmission to others.

HTLV-III/LAV – Continued

References

1. Scott GB, Buck BE, Leterman JG, Bloom FL, Parks WP. Acquired immunodeficiency syndrome in infants. N Engl J Med 1984;310:76-81.
2. Thomas PA, Jaffe HW, Spira TJ, Reiss R, Guerrero IC, Auerbach D. Unexplained immunodeficiency in children. A surveillance report. JAMA 1984;252:639-44.
3. Rubinstein A, Sicklick M, Gupta A, et al. Acquired immunodeficiency with reversed T4/T8 ratios in infants born to promiscuous and drug-addicted mothers. JAMA 1983;249:2350-6.
4. Oleske J, Minnefor A, Cooper R Jr, et al. Immune deficiency syndrome in children. JAMA 1983;249:2345-9.
5. Ziegler JB, Cooper DA, Johnson RO, Gold J. Postnatal transmission of AIDS-associated retrovirus from mother to infant. Lancet 1985;i:896-8.
6. CDC. Unpublished data.
7. Kaplan JE, Oleske JM, Getchell JP, et al. Evidence against transmission of HTLV-III/LAV in families of children with AIDS. Pediatric Infectious Disease (in press).
8. Lewin EB, Zack R, Ayodele A. Communicability of AIDS in a foster care setting. International Conference on Acquired Immunodeficiency Syndrome (AIDS). Atlanta, Georgia, April 1985.
9. Thomas PA, Lubin K, Enlow RW, Getchell J. Comparison of HTLV-III serology, T-cell levels, and general health status of children whose mothers have AIDS with children of healthy inner city mothers in New York. International Conference on Acquired Immunodeficiency Syndrome (AIDS). Atlanta, Georgia, April 1985.
10. Fischl MA, Dickinson G, Scott G, Klimas N, Fletcher M, Parks W. Evaluation of household contacts of adult patients with the acquired immunodeficiency syndrome. International Conference on Acquired Immunodeficiency Syndrome (AIDS). Atlanta, Georgia, April 1985.
11. Friedland GH, Saltzman BR, Rogers MF, et al. Lack of household transmission of HTLV-III infection. EIS Conference. Atlanta, Georgia, April 1985.

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December 6, 1985 / Vol. 34 / No. 48

MMWR

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Current Trends

Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immunodeficiency Syndrome

The information and recommendations in this document are intended to assist health-care providers and state and local health departments in developing procedures to prevent perinatal transmission of human T-lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV), the virus that causes acquired immunodeficiency syndrome (AIDS).

This document contains recommendations for providing counselling and, when indicated, testing for antibody to HTLV-III/LAV for women who are at increased risk of acquiring the virus and who are either pregnant or may become pregnant. It is important that these women know they are at risk, as well as know and understand their HTLV-III/LAV-antibody status, so they can make informed decisions to help prevent perinatally acquired HTLV-III/LAV.

Through counselling, uninfected women can learn how to avoid becoming infected, and infected women can choose to delay pregnancy until more is known about perinatal transmission of the virus. If already pregnant, infected women can be provided information for managing the pregnancy and caring for the child.

Currently available data indicate that most pediatric HTLV-III/LAV infections and AIDS are acquired perinatally from infected women, but additional studies are needed to better quantify the risk of transmission from an infected pregnant woman to the fetus or newborn.

The recommendations below pertain to women. However, men who are HTLV-III/LAV-antibody positive should also be counselled regarding the risks of sexual and perinatal transmission, so they can refer for counselling and testing their sex partners who may be pregnant or considering pregnancy.

BACKGROUND

Pediatric AIDS Cases due to Perinatal Transmission. As of December 1, 1985, 217 (1%) of the 15,172 AIDS cases reported to CDC occurred among children under 13 years of age. Sixty percent of these children are known to have died. These 217 cases represent only the more severe manifestations of HTLV-III/LAV infection. Less severe manifestations, often described as AIDS-related complex (ARC), are not reported to CDC, so the number of children with clinically significant illness attributable to HTLV-III/LAV infection is greater than the reported cases of pediatric AIDS. In addition, a number of infected children are probably asymptomatic.

HTLV-III/LAV — Continued

Of the 217 reported pediatric AIDS patients, 165 (76%) have as their only known risk factor a mother belonging to a group with increased prevalence of HTLV-III/LAV infection. An additional 18% of the pediatric cases are attributable to transfusions of blood or blood products, while risk factor information is missing or incomplete on the remaining 6%. Of the 217 children with AIDS, 48% had mothers who were intravenous (IV) drug abusers, 17% had mothers who were born in Haiti, and 10% had mothers who were sex partners of either IV drug abusers or bisexual men.

Of the patients with perinatally acquired AIDS, 45% resided in New York City, while Florida and New Jersey accounted for an additional 32%.

Mechanisms of Perinatal Transmission. It is believed that HTLV-III/LAV is transmitted from infected women to their fetuses or offspring during pregnancy, during labor and delivery, or perhaps shortly after birth. Transmission of the virus during pregnancy or labor and delivery is demonstrated by two reported AIDS cases occurring in children who had no contact with their infected mothers after birth. One was delivered by Caesarean section (*1,2*).

Transmission of the virus after birth has been implicated in one case of HTLV-III/LAV infection in a child born to a mother reported to have acquired the infection from a postpartum blood transfusion. Since she breastfed the child for 6 weeks, the authors suggested breastfeeding as the possible mode of transmission (*3*). Recently, HTLV-III/LAV has been isolated from the breast milk of infected women (*4*).

Risk of Perinatal Transmission from Infected Mothers. The rate of perinatal transmission of HTLV-III/LAV from infected pregnant women is unknown; however, available data suggest a high rate. In one study of 20 infants born to infected mothers who had already delivered one infant with AIDS, 13 (65%) had serologic and/or clinical evidence of infection with HTLV-III/LAV several months after birth (*5,6*). Since these women were selected on the basis of having previously transmitted HTLV-III/LAV perinatally, this study may overestimate the average risk of transmission for all infected pregnant women.

Perinatal transmission from an infected mother to her newborn is not inevitable. Of three children born to women who became infected with HTLV-III/LAV by artificial insemination from an infected donor, all were in good health and negative for antibody to the virus more than 1 year after birth (*7*). Another child, born to a woman who was already pregnant at the time of AIDS diagnosis and was demonstrated to be viremic, was seronegative, culture negative, and healthy at birth and at 4 months of age (*8*). In a retrospective study evaluating nine children under 5 years of age whose mothers were later diagnosed with AIDS, two (22%) had antibody to HTLV-III/LAV (*9*). The infection status of these women during pregnancy was unknown.

In these studies, the rate of transmission ranged from 0% (0/3) to 65% (13/20). Additional studies are needed to better define the rate of transmission and variables associated with it.

Risk of Illness among Infected Pregnant Women. Pregnancy is associated with suppression of cell-mediated immunity and increased susceptibility to some infections (*10*). The T-helper to T-suppressor ratio is decreased during normal pregnancy, being lowest in the third trimester, and returns to normal approximately 3 months postpartum (*10*). It is not known whether pregnancy increases an infected woman's risk of developing AIDS or ARC, but one study suggests it does (*6*). Fifteen infected women who were well at time of delivery were followed an average of 30 months after the births of their children. Five (33%) subsequently developed AIDS, seven (47%) developed AIDS-related conditions, and only three (20%) remained asymptomatic. These results may not apply to all infected pregnant women, but they do suggest an increased likelihood of developing disease when an HTLV-III/LAV infection occurs in association with pregnancy.

HTLV-III/LAV – Continued

Prevalence of HTLV-III/LAV Infection. Counseling and testing for antibody to HTLV-III/LAV, when indicated, to reduce perinatal transmission of AIDS will be most beneficial in populations of women with increased prevalence of the virus (Table 1). These include: women who have used drugs intravenously for nonmedical purposes, women who were born in countries where heterosexual transmission is thought to play a major role (*11,12*), women who have engaged in prostitution, and women who are or have been sex partners of men who abuse IV drugs, are bisexual, have hemophilia, were born in countries where heterosexual transmission is thought to play a major role (*11,12*), or have evidence of HTLV-III/LAV infection.

The prevalence of antibody to HTLV-III/LAV in U.S. populations of men and women ranges from less than 0.01% in female blood donors to as high as 74% in men with hemophilia (*13-15*). Among heterosexual IV drug abusers, the prevalence of HTLV-III/LAV infection ranges from 2% to 59% in various geographic areas (*16,17*). Seroprevalence among the heterosexual partners of persons at increased risk for AIDS varies from 10% in female partners of asymptomatic, seropositive hemophilia patients to 71% in the female partners of men with AIDS or ARC (*18-20*). Among prostitutes, the HTLV-III/LAV antibody prevalence varies from 5% to 40%, depending on geographic area, with most of the women with positive tests reflecting histories of IV drug abuse (*21*). Among female blood donors in Atlanta, Georgia, who denied belonging to high-risk groups, 0.01% had repeatedly reactive enzyme-linked immun sorbent assays (ELISAs) followed by reactive Western blot tests (*15*).

TABLE 1. Prevalence of HTLV-III/LAV antibody in heterosexual populations — United States

Populations	Location	No. tested	Prevalence (%)
Intravenous drug abusers (*16,17*)	New York City	274	59
	NJ* < 5 miles from NYC†	204	56
	NJ 5-10 miles from NYC	124	43
	NJ > 100 miles from NYC	88	2
	San Francisco	53	9
Persons with hemophilia (*13,14*)			
Factor VIII concentrate recipients		234	74
Factor IX concentrate recipients		38	39
Cryoprecipitate only recipients		15	40
Female prostitutes (*21*)	Seattle, Washington	92	5
	Miami, Florida	25	40
Female sex partners of men with AIDS or ARC			
(two separate studies) (*19,20*)		7	71
		42	47
Female sex partners of men with asymptomatic HTLV-III/LAV infection (*18*)		21	10
Haitians (*12*)	New York City	87	4
	Miami, Florida	120	8
Female blood donors (*15*)	Atlanta, Georgia	28,394	0.01

*New Jersey

†New York City

Commercially available tests to detect antibody to HTLV-III/LAV are ELISAs using antige derived from whole disrupted HTLV-III/LAV. When the ELISA is reactive on initial testing, i standard procedure to repeat the test on the same specimen. Repeatedly reactive tests a highly sensitive and specific for antibody to HTLV-III/LAV. However, when the ELISA is use to screen populations in which the prevalence of infection is very low (such as blood dono or women not in high-risk groups), the proportion of repeatedly reactive results that are false positive will be higher. For that reason, an additional test, such as a Western blot, is recon mended following repeatedly reactive ELISA results, especially in low-prevalence population In populations with high prevalence of infection (e.g., homosexual men or IV drug abusers most repeatedly reactive ELISAs are reactive by Western blot or another test. For exampl among 109 IV drug abusers whose sera were repeatedly reactive by ELISA, over 85% we reactive by Western blot (*22*). In contrast, in a low-prevalence population of 69 female blo donors whose sera were repeatedly reactive by ELISA, only 5% were reactive by Western bl (*15*).

Due to the seriousness of the implications of HTLV-III/LAV-antibody reactivity, it is recon mended that repeatedly reactive ELISAs be followed by an additional test, such as the Wes ern blot. Women with sera repeatedly reactive by ELISA and reactive by Western blot shou have a thorough medical evaluation. HTLV-III/LAV has been isolated from a single specim in 67%-95% of persons with specific antibody (*23,24*). Because infection has bee demonstrated in asymptomatic persons, the presence of specific antibody should be consi ered presumptive evidence of current infection and infectiousness.

RECOMMENDATIONS

Women Who Should be Offered Counseling and Testing. *Counseling services and tes ing for antibody to HTLV-III/LAV should be offered to pregnant women and women who m become pregnant in the following groups:* (1) those who have evidence of HTLV-III/LAV infe tion, (2) those who have used drugs intravenously for nonmedical purposes, (3) those wh were born in countries where heterosexual transmission is thought to play a major ro (*11,12*), (4) those who have engaged in prostitution, (5) those who are or have been s partners of IV drug abusers, bisexual men, men with hemophilia, men who were born in cou tries where heterosexual transmission is thought to play a major role (*11,12*), or men wh otherwise have evidence of HTLV-III/LAV infection. If data become available to show th HTLV-III/LAV-antibody prevalence is increased in other groups or settings, counseling a testing programs should be extended to include them. Routine counseling and testing women who are not included in the above-mentioned groups is not recommended due to l prevalence of infection and concern about interpretation of test results in a low-prevalen population. However, if a woman requests it, the service should be provided in accordan with these recommendations.

Settings for Offering Counseling and Testing. Counseling and testing for antibody HTLV-III/LAV to prevent perinatal transmission is recommended in the setting of any medi service in which women at increased risk are commonly encountered. These include servi for treating IV drug abuse (i.e., detoxification and methadone maintenance), comprehens hemophilia treatment centers, sexually transmitted disease clinics, and clinics that se female prostitutes. In addition, services related to reproduction, such as family planning a infertility services, gynecologic, premarital, or preconceptual examinations, and prenatal

HTLV-III/LAV – Continued

obstetric services should also consider offering counselling and testing if high-risk women are seen at these facilities. Testing for antibody to HTLV-III/LAV should be performed with the woman's consent after counselling is provided regarding risk factors for infection, the interpretation of test results, the risks of transmission, and the possible increased likelihood of disease among women infected with HTLV-III/LAV in association with pregnancy. The counselling and testing must be conducted in an environment in which confidentiality can be assured. In settings where confidential counselling and testing cannot be assured, information should be provided and referrals made to appropriate facilities.

Frequency of Testing. Detectable antibodies to HTLV-III/LAV may not develop until 2-4 months after exposure. This, and whether the woman is continuously exposed, should be taken into account when considering the need for, and frequency of, repeat testing. High-risk women should be offered counselling and testing before they become pregnant. During pregnancy, counselling and testing should be offered as soon as the woman is known to be pregnant. If the initial test is negative, repeat testing may be indicated near delivery to aid in the clinical management of the pregnant woman and newborn. If the final test is negative and the mother's risk of exposure no longer exists, she may safely consider breastfeeding the child, and management of the child need not include the same concerns that would be appropriate if the woman had had a positive test or if she were at high risk and had not been tested at all.

Counselling Women with Positive Results. Women with virologic or serologic evidence of HTLV-III/LAV infection should be counselled regarding their own risk of AIDS and the risk of perinatal and sexual transmission of HTLV-III/LAV. Infected women should be counselled to refer their sex partners for counselling and testing. If the partners of these women are not infected, both members of the couple should be counselled on how they may modify their sexual practices to reduce the risk of HTLV-III/LAV transmission to the uninfected partner. In addition, the couple should be told not to donate blood, organs, or sperm and should be discouraged from using IV drugs and advised against sharing needles and syringes. When seeking medical or dental care for intercurrent illness, they should inform those responsible for their care of their positive antibody status so appropriate evaluation can be undertaken. Recommendations for providing information and advice to individuals infected with HTLV-III/LAV have been published (25).

Infected women should be advised to consider delaying pregnancy until more is known about perinatal transmission of the virus. Pregnant infected women may require additional medical and social support services due to an enhanced risk of opportunistic infections and psychosocial difficulties during and after pregnancy. Obstetric-care providers should be alert to signs and symptoms of HTLV-III/LAV and related opportunistic infections in these pregnant women and to the need for specialized medical care.

HTLV-III/LAV-infected women should be advised against breastfeeding to avoid postnatal transmission to a child who may not yet be infected. The child should receive follow-up pediatric evaluations to determine whether he/she has HTLV-III/LAV infection, and to diagnose and treat promptly any diseases that may be secondary to HTLV-III/LAV infection. Recommendations for educating and providing foster care for infected children have been published (26).

Counselling Women with Negative Test Results. A negative ELISA for HTLV-III/LAV antibody in women who have no clinical or laboratory evidence of HTLV-III/LAV infection is evidence that they have probably not been infected. However, uninfected women who have sex partners with evidence of HTLV-III/LAV infection or with an increased risk of becoming infected should be informed that sexual intercourse increases their risk of infection. These women should be informed of the risks associated with pregnancy if they become infected and advised to consider delaying pregnancy until more is known about perinatal transmission of the virus or until they are no longer considered to be at risk for acquiring the virus. In addition to preventing pregnancy, the consistent and proper use of condoms can offer some protection against HTLV-III/LAV infection.

HTLV-III/LAV – Continued

High-risk women, even if seronegative, should be told not to donate blood or organs. To decrease their risk of becoming infected, IV drug abusers should be encouraged to seek treatment for their drug abuse. Persons counselling IV drug abusers should know that IV drug abuse is often strongly ingrained and compulsive. Despite educational efforts and encouragement for treatment, some addicts will continue to abuse drugs or relapse after treatment. If drug abuse continues, they should be advised not to share needles or syringes and to use only sterile equipment.

Additional Considerations: These recommendations will be revised as additional information becomes available. It is recognized that provision of the recommended professional counseling, HTLV-III/LAV-antibody testing, and associated specialized medical services will take time to implement and may stress available resources, particularly in public facilities, which are most greatly affected. Health-care providers, social-service personnel, and others involved in educating and caring for HTLV-III/LAV-infected persons should be aware of the potential for social isolation and should be sensitive to the need for confidentiality. They should be familiar with federal and state laws, regulations, and policies that protect the confidentiality of clinical data and test results. Each institution should assure that specific mechanisms are in place to protect the confidentiality of all records and to prevent the misuse of information. Anonymous testing would not be appropriate if it prevents adequate counseling and medical follow-up evaluation.

Hospital precautions for managing infected women and infants should be patterned after those for caring for patients with HTLV-III/LAV infection (*27,28*). Additional recommendations will follow.

DEVELOPMENT OF THESE RECOMMENDATIONS

The information and recommendations contained in this document were developed and compiled by CDC and the U.S. Public Health Service in consultation with individuals representing: the Conference of State and Territorial Epidemiologists, the Association of State and Territorial Health Officials, the American Public Health Association, the United States Conference of Local Health Officers, the American Medical Association, the American College of Obstetricians and Gynecologists, the American Academy of Pediatrics, the Planned Parenthood Federation of America, the American Venereal Disease Association, the Division of Maternal and Child Health of the Health Resources and Services Administration, the National Institute on Drug Abuse of the Alcohol, Drug Abuse, and Mental Health Administration, the National Hemophilia Foundation, the Haitian Medical Association, the American Bar Foundation, and the Kennedy Institute of Ethics at Georgetown University. The consultants also included representatives of the departments of health of the areas with the largest number of perinatally transmitted pediatric AIDS cases: New York City, Florida, and New Jersey. These recommendations may not reflect the views of all individual consultants or the organizations they represented.

References

1. Lapointe N, Michaud J, Pekovic D, Chausseau JP, Dupuy JM. Transplacental transmission of HTLV-III virus [Letter]. N Engl J Med 1985;312:1325-6.
2. Cowan MJ, Hellmann D, Chudwin D, Wara DW, Chang RS, Ammann AJ. Maternal transmission of acquired immune deficiency syndrome. Pediatrics 1984;73:382-6.
3. Ziegler JB, Cooper DA, Johnson RO, Gold J. Postnatal transmission of AIDS-associated retrovirus from mother to infant. Lancet 1985;i:896-7.
4. Thiry L, Sprecher-Goldberger S, Jonckheer T, et al. Isolation of AIDS virus from cell-free breast milk of three healthy virus carriers [Letter]. Lancet 1985;ii:891-2.
5. Scott GB, Fischl MA, Klimas N, et al. Mothers of infants with the acquired immunodeficiency syndrome: outcome of subsequent pregnancies. Atlanta, Georgia: International conference on acquired immunodeficiency syndrome, April 14-17, 1985.
6. Scott GB, Fischl MA, Klimas N, et al. Mothers of infants with the acquired immunodeficiency syndrome: evidence for both symptomatic and asymptomatic carriers. JAMA 1985;253:363-6.
7. Stewart GJ, Tyler JPP, Cunningham AL, et al. Transmission of human T-lymphotropic virus type III (HTLV-III) virus by artificial insemination by donor. Lancet 1985;ii:581-4.
8. CDC. Unpublished data.
9. Thomas PA, Lubin K, Enlow RW, Getchell J. Comparison of HTLV-III serology, T-cell levels, and general health status of children whose mothers have AIDS with children of healthy inner city

mothers in New York. Atlanta, Georgia: International conference on acquired immunodeficiency syndrome, April 14-17, 1985.
10. Weinberg ED. Pregnancy-associated depression of cell-mediated immunity. Rev Inf Dis 1984;6:814-31.
11. WHO. Acquired immune deficiency syndrome (AIDS): Report on the situation in Europe as of 31 December 1984. Weekly Epidemiological Record 1985;60:85-92.
12. Castro KG, Fischl MA, Landesman SH, et al. Risk factors for AIDS among Haitians in the United States. Atlanta, Georgia: International conference on acquired immunodeficiency syndrome, April 14-17, 1985.
13. Jason J, McDougal JS, Holman RC, et al. Human T-lymphotropic retrovirus type III/lymphadenopathy-associated virus antibody: association with hemophiliacs' immune status and blood component usage. JAMA 1985;253:3409-15.
14. Gjerset GF, McGrady G, Counts RB, et al. Lymphadenopathy-associated virus antibodies and T cells in hemophiliacs treated with cryoprecipitate or concentrate. Blood 1985;66:718-20.
15. CDC. Unpublished data.
16. Spira TJ, Des Jarlais DC, Bokos D, et al. HTLV-III/LAV antibodies in intravenous drug abusers: comparison of low and high risk areas for AIDS. Atlanta, Georgia: International conference on acquired immunodeficiency syndrome, April 14-17, 1985.
17. Weiss SH, Ginzburg HM, Goedert JJ, et al. Risk for HTLV-III exposure and AIDS among parenteral drug abusers in New Jersey. Atlanta, Georgia: International conference on acquired immunodeficiency syndrome, April 14-17, 1985.
18. Kreiss JK, Kitchen LW, Prince HE, Kasper CK, Essex M. Antibody to human T-lymphotropic virus type III in wives of hemophiliacs: evidence for heterosexual transmission. Ann Intern Med 1985;102:623-6.
19. Redfield RR, Markham PD, Salahuddin SZ, et al. Frequent transmission of HTLV-III among spouses of patients with AIDS-related complex and AIDS. JAMA 1985;253:1571-3.
20. Harris CA, Cabradilla CD, Robert-Guroff M, et al. HTLV-III/LAV infection and AIDS in heterosexual partners of AIDS patients. Minneapolis, Minnesota: Twenty-fifth interscience conference on antimicrobial agents and chemotherapy, September 29-October 2, 1985.
21. CDC. Heterosexual transmission of human T-lymphotropic virus type III/lymphadenopathy-associated virus. MMWR 1985;34:561-3.
22. CDC. Unpublished data.
23. Feorino PM, Jaffe HW, Palmer E, et al. Transfusion-associated acquired immunodeficiency syndrome: evidence for persistent infection in blood donors. N Engl J Med 1985;312:1293-6.
24. Jaffe HW, Feorino PM, Darrow WW, et al. Persistent infection with human T-lymphotropic virus type III/lymphadenopathy-associated virus in apparently healthy homosexual men. Ann Intern Med 1985;102:627-30.
25. CDC. Provisional Public Health Service inter-agency recommendations for screening donated blood and plasma for antibody to the virus causing acquired immunodeficiency syndrome. MMWR 1985;34:1-5.
26. CDC. Education and foster care of children infected with human T-lymphotropic virus type III/lymphadenopathy-associated virus. MMWR 1985;34:517-21.
27. CDC. Acquired immune deficiency syndrome (AIDS): precautions for clinical and laboratory staffs. MMWR 1982;31:577-80.
28. CDC. Recommendations for preventing transmission of infection with human T-lymphotropic virus type III/lymphadenopathy-associated virus in the workplace. MMWR 1985;34:681-6, 691-5.

Assembly Bill No. 403

CHAPTER 22

An act to add Chapter 1.11 (commencing with Section 199.20) to Part 1 of Division 1 of the Health and Safety Code, relating to health, and declaring the urgency thereof, to take effect immediately.

[Approved by Governor April 3, 1985. Filed with
Secretary of State April 4, 1985.]

LEGISLATIVE COUNSEL'S DIGEST

AB 403, Agnos. Health.

(1) Existing law provides that the results of specified blood tests shall be confidential and not open to public inspection.

This bill, in addition to existing law, would provide that no person shall be compelled, as specified, to identify any individual who is the subject of a blood test to detect antibodies to the probable causative agent of acquired immune deficiency syndrome. The bill would provide penalties for disclosure, as defined, of the results of the blood test, as defined, except as specified, including the assessing of civil penalties and the creation of a new misdemeanor. It would establish a right of action for actual damages. Creation of a new misdemeanor constitutes a state-mandated local program.

This bill would permit the State Department of Health Services to require blood banks and plasma centers to submit reports summarizing data concerning tests to detect the presence of viral hepatitis and antibodies to the probable causative agent of AIDS, as specified.

It would prohibit a person, except as specified, from testing a person's blood for evidence of antibodies to the probable causative agent of AIDS without the written consent of the subject.

This bill would prescribe that the results of the blood test not be used in any instance for the determination of insurability or suitability for employment.

It would also prescribe that neither the state department nor any blood bank or plasma center, including a blood bank or plasma center operated by a public entity, be liable for any damages resulting from a specified notification of test results.

(2) The California Constitution requires the state to reimburse local agencies and school districts for certain costs mandated by the state. Statutory provisions establish procedures for making that reimbursement, including the creation of a State Mandates Claims Fund to pay the costs of mandates which do not exceed $500,000 statewide and other procedures for claims whose statewide costs exceed $500,000.

This bill would provide that no reimbursement shall be made from the State Mandates Claims Fund for costs mandated by the state

pursuant to this act, but would recognize that local agencies and school districts may pursue any available remedies to seek reimbursement for some of these costs.

This bill would provide that, notwithstanding Section 2231.5 of the Revenue and Taxation Code, this bill does not contain a repealer, as required by that section; therefore, the provisions of the bill would remain in effect unless and until they are amended or repealed by a later enacted bill.

The bill would take effect immediately as an urgency statute.

The people of the State of California do enact as follows:

SECTION 1. Chapter 1.11 (commencing with Section 199.20) is added to Part 1 of Division 1 of the Health and Safety Code, to read:

CHAPTER 1.11. MANDATED BLOOD TESTING AND CONFIDENTIALITY TO PROTECT PUBLIC HEALTH

199.20. To protect the privacy of individuals who are the subject of blood testing for antibodies to the probable causative agent of acquired immune deficiency syndrome (AIDS) the following shall apply:

Except as provided in Section 1603.1 or 1603.3, as amended by AB 488 of the 1985–86 Regular Session, no person shall be compelled in any state, county, city, or other local civil, criminal, administrative, legislative, or other proceedings to identify or provide identifying characteristics which would identify any individual who is the subject of a blood test to detect antibodies to the probable causative agent of AIDS.

199.21. (a) Any person who negligently discloses results of a blood test to detect antibodies to the probable causative agent of acquired immune deficiency syndrome to any third party, except pursuant to a written authorization, as described in subdivision (g), or except as provided in Section 1603.1 or 1603.3, as amended by AB 488 of the 1985–86 Regular Session, shall be assessed a civil penalty in an amount not to exceed one thousand dollars ($1,000) plus court costs, as determined by the court, which penalty and costs shall be paid to the subject of the test.

(b) Any person who willfully discloses the results of a blood test to detect antibodies to the probable causative agent of the acquired immune deficiency syndrome, to any third party, except pursuant to a written authorization, as described in subdivision (g), or except as provided in Section 1603.1 or 1603.3, as amended by AB 488 of the 1985–86 Regular Session, shall be assessed a civil penalty in an amount not less than one thousand dollars ($1,000) and not more than five thousand dollars ($5,000) plus court costs, as determined by the court, which penalty and costs shall be paid to the subject of the test.

(c) Any person who willfully or negligently discloses the results of a blood test to detect antibodies to the probable causative agent of acquired immune deficiency syndrome to a third party, except pursuant to a written authorization, as described in subdivision (g), or except as provided in Section 1603.1 or 1603.3, as amended by AB 488 of the 1985–86 Regular Session, which results in economic, bodily, or psychological harm to the subject of the test, is guilty of a misdemeanor, punishable by imprisonment in the county jail for a period not to exceed one year or a fine of not to exceed ten thousand dollars ($10,000) or both.

(d) Any person who commits any act described in subdivision (a) or (b) shall be liable to the subject for all actual damages, including damages for economic, bodily, or psychological harm which is a proximate cause of the act.

(e) Each disclosure made in violation of this chapter is a separate and actionable offense.

(f) The results of a blood test to detect antibodies to the probable causative agent of acquired immune deficiency syndrome shall not be used in any instance for the determination of insurability or suitability for employment.

(g) "Written authorization," as used in this section, applies only to the disclosure of test results by a person responsible for the care and treatment of the person subject to the test. Written authorization is required for each separate disclosure of the test results, and shall include to whom the disclosure would be made.

(h) Nothing in this section limits or expands the right of an injured subject to recover damages under any other applicable law.

(i) Nothing in this section shall be construed to impose liability or criminal sanction for disclosure of a blood test to detect antibodies to the probable causative agent of AIDS in accordance with any reporting requirement for a diagnosed case of AIDS by the state department or the Centers for Disease Control under the United States Public Health Services.

(j) The state department may require blood banks and plasma centers to submit monthly reports summarizing statistical data concerning the results of tests to detect the presence of viral hepatitis and antibodies to the probable causative agent of AIDS. This statistical summary shall not include the identity of individual donors or identifying characteristics which would identify individual donors.

(k) "Disclosed," as used in this section, means to disclose, release, transfer, disseminate, or otherwise communicate all or any part of any record orally, in writing, or by electronic means to any person or entity.

(*l*) "Results of a blood test," as used in this section, means to identify or provide identifying characteristics of the person to whom the results apply.

199.22. No person shall test a person's blood for evidence of antibodies to the probable causative agent of AIDS without the written consent of the subject of the test, and the person giving the test shall have a written statement signed by the subject confirming that he or she obtained the consent from the subject.

This requirement does not apply to a test performed at an alternative site, as established pursuant to Article 8 (commencing with Section 1630) of Chapter 4 of Division 2. This requirement also does not apply to any blood and blood products specified in paragraph (2) of subdivision (a) of Section 1603.1, as amended by Assembly Bill 488 of the 1985–86 Regular Session.

199.23. Neither the state department nor any blood bank or plasma center, including a blood bank or plasma center owned or operated by a public entity, shall be held liable for any damages resulting from the notification of test results, as set forth in paragraph (3) of subdivision (a) of, and in subdivision (c) of, Section 1603.3, as amended by AB 488 of the 1985–86 Regular Session.

SEC. 2. (a) No reimbursement is required by this act pursuant to Section 6 of Article XIII B of the California Constitution because part of the costs which may be incurred by a local agency or school district will be incurred because this act creates a new crime or infraction, changes the definition of a crime or infraction, changes the penalty for a crime or infraction, or eliminates a crime or infraction.

(b) No reimbursement shall be made from the State Mandates Claims Fund pursuant to Part 7 (commencing with Section 17500) of Division 4 of Title 2 of the Government Code for costs mandated by the state pursuant to this act. It is recognized, however, that a local agency or school district may pursue any remedies to obtain reimbursement available to it under Part 7 (commencing with Section 17500) and any other provisions of law.

SEC. 3. Notwithstanding Section 2231.5 of the Revenue and Taxation Code, this act does not contain a repealer, as required by that section; therefore, the provisions of this act shall remain in effect unless and until they are amended or repealed by a later enacted act.

SEC. 4. This act is an urgency statute necessary for the immediate preservation of the public peace, health, or safety within the meaning of Article IV of the Constitution and shall go into immediate effect. The facts constituting the necessity are:

In order to protect the confidentiality of persons undergoing a blood test for the detection of anitbodies to acquired immune deficiency syndrome, and to encourage individuals who are stricken with the disease to undergo treatment which would ultimately benefit the health and welfare of all citizens of the State of California, it is necessary that this act take immediate effect.

O

Education of Children Infected with Human T-Lymphotropic Virus-Type III/Lymphadenopathy-Associated Virus

Pediatric AIDS Advisory Committee
Department of Public Health
City and County of San Francisco

February 18, 1986

The information and recommendations contained in this document were developed and compiled by a special task force of the Department of Public Health, City and County of San Francisco, which included representatives of the Department of Pediatrics, University of California, San Francisco; the San Francisco Unified School District; and the Department of Public Health.

These recommendations apply to all pre-school and school-aged children infected with human T-lymphotropic virus-type III/lymphadenopathy-associated virus (HTLV-III/LAV). These include children with Centers for Disease Control (CDC)-defined AIDS, children with lesser clinical manifestations of HTLV-III/LAV infection such as AIDS-related complex (ARC), and children with asymptomatic HTLV-III/LAV infection.

BACKGROUND

Pediatric AIDS

The infection of children with HTLV-III/LAV has been well established (1). Unlike adult HTLV-III/LAV infection where the primary mode of virus transmission is through sexual contact, the primary modes of transmission in childhood HTLV-III/LAV infection are perinatal (2-11) and parenteral (12-13). Infants and children infected with HTLV-III/LAV demonstrate a full range of host responses, from asymptomatic infection to frank clinical AIDS. It is not, however, known what proportion of infected children will develop clinical disease nor what the long-term natural history of childhood HTLV-III/LAV infection is. As of February 3, 1986, 242 cases of pediatric AIDS have been reported to the CDC (14). One hundred eighty-three (76 percent) of these children were born to mothers who either had AIDS or were at increased risk for AIDS. An additional 45 (19 percent) children were infected through transfusions of blood or blood products, and 14 (6 percent) had unknown sources of infection. Thus, 76 of cases had been infected with HTLV-III/LAV perinatally and 19 percent parenterally.

Perinatally infected infants who develop AIDS first develop symptoms at a median age of four months and approximately one half of these infants will be diagnosed as having AIDS by their first birthday (1). Only five percent of perinatally infected infants are diagnosed at five years of age or older. Typical prodomal systems include failure to thrive, recurrent or persistent thrush, chronic intestitial pneumonitis hepatosplenomegaly, chronic or recurrent diarrhea, lymphadenopathy, and severe recurrent bacterial infection, such as sepsis and meningitis. When frank clinical AIDS develops in these patients the most common diagnosis is *Pneumocystis carinii* pneumonia (62 percent), and the second most common is an other opportunistic infection without Kaposi's sarcoma or *Pneumocystis carinii* pneumonia (33 percent) (1). Similarily, children infected parenterally through infected blood transfusions present with symptoms of AIDS at a median age of one year. Their clinical symptoms and course are very similar to children perinatally infected with HTLV-III/LAV. Children, primarily hemophiliacs, parenterally infected through transfusion of infected blood products, however, present in the second decade of life with a median age of fourteen years. Their symptoms tend to more closely mirror those of adult AIDS patients (1).

HTLV-III/LAV Transmissions in Households

None of the identified cases of HTLV-III/LAV infection in the United States are known to have been transmitted in school, day care, or foster care settings, or through other casual person-to-person contact (15). Other than sexual partners of HTLV-III/LAV-infected patients and infants born to infected mothers, none of the family members of the over 16,000 AIDS patients reported to CDC have developed AIDS. Five studies of family members of patients with HTLV-III/LAV infection have failed to demonstrate HTLV-III/LAV transmission to adults who are not sexual contacts of the infected patients or to children who have not already been infected perinatally (16-20). However, if casual person-to-person transmission of HTLV-III/LAV infection does exist, it should theoretically be greatest among young children. This theoretical transmission would most likely involve exposure of open skin lesions or mucous membranes to blood and possibly other body fluids of an infected person. We emphasize that there is *no* evidence of this type of transmission occurring in any setting at this time.

Legal Issues.

The following legal issues are salient to these guideline: the civil rights aspects of public school attendance, the protection of handicapped children under 20 U.S.C. 1401 *et seq.* and 29 U.S.C. 794, confidentiality of a student school record under 20 U.S.C. 1232 g, and the confidentiality of anti-HTLV-III antibody test results under California Health and Safety Code 199.21, and the protection of AIDS patients against discrimination under the San Francisco AIDS Anti-Discrimination Ordinance.

Confidentiality Issues

The diagnoses of AIDS or AIDS-associated illnesses evoke much fear from others in contact with the patient and may evoke suspicion of lifestyles that may not be acceptable to some persons. Parents of HTLV-III/LAV-infected children should be aware of potential for isolation should the child's condition become known to others in the educational setting. School and social service personnel and others involved in educating these children should be sensitive to the need for confidentiality and the right to privacy in these cases.

CDC Guidelines

On August 30, 1985, CDC published guidelines for the education of foster care of children infected with HTLV-III/LAV (15) (Attachment A). The basic guidelines which apply to pre-school and school-aged children are numbers 1,2,3,4,5,6,7,9,10 and 11.

RECOMMENDATIONS

1. Education

Because of enormous public concern we recommend that the San Francisco Unified School District continue its efforts to educate parents, students, and school personnel about AIDS, HTLV-III/LAV infection, HTLV-III/LAV transmission, and the social implications of AIDS and HTLV-III/LAV infection. Especially important is the proposed addition of a module on AIDS and HTLV-III/LAV in the family life education curriculum.

2. School Personnel

There is no known reason for testing school personnel under any circumstance whatsoever. We recommend that school personnel not be screened for HTLV-III/LAV infection.

3. Students

At the present time there are very few, if any, pre-school and school-aged children infected with HTLV-III/LAV in San Francisco. Because of the intense publicity surrounding the enrollment of AIDS patients in public schools and incidents of breaches of confidentiality and frank discrimination, parents of infected children are undoubtedly reluctant to reveal their child's infection. However, in order to protect an HTLV-III/LAV-infected child from infections in the classroom and to promptly notify the child's medical provider when exposures to potentially life-threatening communicable diseases occur, it is to the child's advantage if someone in the school is aware that the child is immunosuppressed. In order to encourage such disclosures, a climate of acceptance, confidentiality, and respect needs to be created through education.

a. Day Care and Pre-School. Until more is known about the risk of HTLV-III/LAV-infected children acquiring potentially harmful infections in day care and pre-school settings, we recommend that HTLV-III/LAV-infected infants and younger pre-school-aged children under three years of age not attend routine day care. We recommend that these children be educated and cared for in restricted settings, i.e., individually, with other HTLV-III/LAV-infected children, or with siblings. In these settings, we recommend that a single provider know of their infection and follow CDC guidelines 4 and 5. Because the risk of fecal-oral transmission of diseases diminishes greatly after toilet training, the benefits of an unrestricted pre-school setting in which all attendees are toilet trained outweigh the risks of an infected child acquiring potentially harmful infections and the apparent nonexistant risk of HTLV-III/LAV transmission. We recommend that, in general, infected pre-school-aged children three years old and older with asymptomatic infection or mild clinical disease can attend pre-school as long as all children in the school are toilet trained. However, because circumstances vary from pre-school to pre-school, we also recommend that the case of each child be considred individually by a small subgroup of this committee with appropriate input from the pre-school to be attended.

b. Elementary and Junior and Senior High Schools. When a child is known to be infected with HTLV-III/LAV, his or her medical history will be reviewed by a joint committee of the Department Public Health and the San Francisco Unified School District and an appropriate class placement will be recommended to the Superintendent of the San Francisco Unified School District. The final decisions involving health matters will rest with the Director of Health. These recommendations will be reviewed annually or more often if requested by the child's principal or family.

4. Confidentiality

We recommend that the Superintendent or his designee be informed that an HTLV-III/LAV-infected child is to be placed in their schools if the child is, in the opinion of the committee, clinically immunosuppressed. As a result of his or her immunosuppression, this child will be exempted from required vaccinations with measles-mumps-rubella vaccine and will need to be excluded from school should exposures to measles, mumps, rubella, or varicella occur. Moreover, the Superintendent or his designee should be informed of the potential severity of the child's immunosuppression and be instructed to notify the child's parent or guardian or the child's medical provider should such exposures occur.

5. Body Secretions and Disinfection Precautions.

We recommend that the precautions outlined by CDC and other infection control guidelines available through the California Department of Education be adopted by the San Francisco Unified School District. We recommend that school personnel be trained in uniform procedures for handling blood and body secretions and that these procedures be observed for cleaning and disinfection of blood and body secretions in the schools. These procedures will also provide protection against other communicable diseases.

CONCLUSIONS

We emphasize that these are interim guidelines which will need to be reviewed as more information becomes available on the natural history of HTLV-III/LAV infection in childhood, household transmission, safety of live virus vaccines, and exposure of HTLV-III/LAV infected children to common communicable diseases. Additionally, as vaccine and definitive antiviral therapy become available, further review will be warranted. Finally, it should be clearly stated that all evidence indicates that there is no risk for casual transmission of HTLV-III/LAV and that the primary intent of these guidelines is to assure appropriate medical care for HTLV-III/LAV-infected pre-school and school-aged children.

REFERENCES

1. Rogers MF. AIDS in children: a review of the clinical, epidemiologic, and public health aspects. *Pediatr Infect Dis* 1985; 4: 230-6.

2. CDC. Unexplained immunodeficiency and opportunistic infections in infants - New York, New Jersey, California. *MMWR* 1982; 31: 665-7.

3. Cowan MJ, Hellman D, Chudwin DL, *et al*. Maternal transmission of acquired immune deficiency syndrome. *Pediatrics* 1984; 73:382-6.

4. Joncas JH, Delage G, Chad Z, *et al*. Acquired (or congenital) immunodeficiency syndrome in infants born of Haitian mothers [letter]. *N Engl J Med* 1983; 308:842.

5. Lapointe N, Michaud J, Pekobic D, *et al*. Transplacental transmission of HTLV-III virus. *N Engl J Med* 1985; 312:1325-6.

6. Oleske J, Minnefor A, Cooper R Jr, *et al*. Immune deficiency syndrome in children. *JAMA* 1983; 249: 2345-9.

7. Rubenstein A, Sicklic M, Gupta A, *et al*. Acquired immunodeficiency syndrome with reversed T4/T8 ratios in infants born to promiscuous and drug-addicted mothers. *JAMA* 1983; 249:2350-6.

8. Scott GB, Buck BE, Letterman JG, *et al*. Acquired immunodeficiency syndrome in infants. *N Engl J Med* 1984; 310: 76-81.

9. Scott GB, Fischl MA, Klimas N, *et al*. Mothers of infants with acquired immunodeficiency syndrome (AIDS): evidence for both symptomatic and asymptomatic carriers. *JAMA* 1985; 253:363-6.

10. Thomas PA, Jaffe HW, Spira TJ, *et al*. Unexplained immunodeficiency in children. *JAMA* 1984; 252: 639-44.

11. Ziegler JF, Cooper DA, Johnson RO, *et al*. Postnatal transmission of AIDS-associated retrovirus from mother to infant. *Lancet* 1985; 1:896-8.

12. CDC. Update: acquired immunodeficiency syndrome (AIDS) in persons with hemophilia. *MMWR* 1984; 33:589-91.

13. Curran JW, Lawrence DN, Jaffe H, *et al*. Acquired immunodeficiency syndrome (AIDS) associated with transfusions. *N Engl J Med* 1984; 310: 69-75.

14. CDC. Unpublished data.

15. CDC. Education and foster care of children infected with human T-lymphotropic virus type III/lymphadenopathy-associated virus. *MMWR* 1985; 34: 517-21.

16. Fischl MA, Dickinson G, Scott G, *et al*. Evaluation of household contacts of adult patients with the acquired immunodeficiency syndrome. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.

17. Friedland GH, Saltzman BR, Rogers MF, *et al*. Lack of transmission of HTLV-III infection to household contacts of patients with AIDS or AIDS-related complex with oral candidiasis. *N Engl J Med* 1986; 314: 344-9.

18. Kaplan JE, Oleske JM, Getchell JP, *et al*. Evidence against transmission of HTLV-III/LAV in families of children with AIDS. *Pediatr Infect Dis* 1985; 4: 468-71.

19. Lewin EB, Zack R, Ayodele A. Communicability of AIDS in a foster care setting. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.

20. Thomas PA, Lubin K, Enlow RW, *et al*. Comparison of HTLV-III serology, T-cell levels, and general health status of children whose mothers have AIDS with children of healthy inner city mothers in New York. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.

CENTERS FOR DISEASE CONTROL

MMWR

MORBIDITY AND MORTALITY WEEKLY REPORT

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Attachment A

517 Education and Foster Care of Children Infected with HTLV-III/LAV
521 Status of the 1990 Physical Fitness and Exercise Objectives
531 Influenza — Southern Hemisphere Asia, the Tropics, March-August 1985
533 Recommendations for Preventing Possible Transmission of HTLV-III/LAV from Tears

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Current Trends

Education and Foster Care of Children Infected with Human T-Lymphotropic Virus Type III/ Lymphadenopathy-Associated Virus

The information and recommendations contained in this document were developed and compiled by CDC in consultation with individuals appointed by their organizations to represent the Conference of State and Territorial Epidemiologists, the Association of State and Territorial Health Officers, the National Association of County Health Officers, the Division of Maternal and Child Health (Health Resources and Services Administration), the National Association for Elementary School Principals, the National Association of State School Nurse Consultants, the National Congress of Parents and Teachers, and the Children's Aid Society. The consultants also included the mother of a child with acquired immunodeficiency syndrome (AIDS), a legal advisor to a state education department, and several pediatricians who are experts in the field of pediatric AIDS. This document is made available to assist state and local health and education departments in developing guidelines for their particular situations and locations.

These recommendations apply to all children known to be infected with human T-lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV). This includes children with AIDS as defined for reporting purposes (Table 1); children who are diagnosed by their physicians as having an illness due to infection with HTLV-III/LAV but who do not meet the case definition, and children who are asymptomatic but have virologic or serologic evidence of infection with HTLV-III/LAV. These recommendations do not apply to siblings of infected children unless they are also infected.

BACKGROUND

The Scope of the Problem. As of August 20, 1985, 183 of the 12,599 reported cases of AIDS in the United States were among children under 18 years of age. This number is expected to double in the next year. Children with AIDS have been reported from 23 states, the District of Columbia, and Puerto Rico, with 75% residing in New York, California, Florida, and New Jersey.

The 183 AIDS patients reported to CDC represent only the most severe form of HTLV-III/LAV infection, i.e., those children who develop opportunistic infections or malignancies (Table 1). As in adults with HTLV-III/LAV infection, many infected children may have milder illness or may be asymptomatic.

Legal Issues. Among the legal issues to be considered in forming guidelines for the education and foster care of HTLV-III/LAV-infected children are the civil rights aspects of public

HTLV-III/LAV – Continued

TABLE 1. Provisional case definition for acquired immunodeficiency syndrome (AIDS) surveillance of children

For the limited purposes of epidemiologic surveillance, CDC defines a case of pediatric acquired immunodeficiency syndrome (AIDS) as a child who has had:

1. A reliably diagnosed disease at least moderately indicative of underlying cellular immunodeficiency, and
2. No known cause of underlying cellular immunodeficiency or any other reduced resistance reported to be associated with that disease.

The diseases accepted as sufficiently indicative of underlying cellular immunodeficiency are the same as those used in defining AIDS in adults. In the absence of these opportunistic diseases, a histologically confirmed diagnosis of chronic lymphoid interstitial pneumonitis will be considered indicative of AIDS unless test(s) for HTLV-III/LAV are negative. Congenital infections, e.g., toxoplasmosis or herpes simplex virus infection in the first month after birth or cytomegalovirus infection in the first 6 months after birth must be excluded.

Specific conditions that must be excluded in a child are:

1. Primary immunodeficiency diseases—severe combined immunodeficiency, DiGeorge syndrome, Wiskott-Aldrich syndrome, ataxia-telangiectasia, graft versus host disease, neutropenia, neutrophil function abnormality, agammaglobulinemia, or hypogammaglobulinemia with raised IgM.
2. Secondary immunodeficiency associated with immunosuppressive therapy, lymphoreticular malignancy, or starvation.

school attendance, the protections for handicapped children under 20 U.S.C. 1401 et seq. and 29 U.S.C. 794, the confidentiality of a student's school record under state laws and under 20 U.S.C. 1232g, and employee right-to-know statutes for public employees in some states.

Confidentiality Issues. The diagnosis of AIDS or associated illnesses evokes much fear from others in contact with the patient and may evoke suspicion of life styles that may not be acceptable to some persons. Parents of HTLV-III/LAV-infected children should be aware of the potential for social isolation should the child's condition become known to others in the care or educational setting. School, day-care, and social service personnel and others involved in educating and caring for these children should be sensitive to the need for confidentiality and the right to privacy in these cases.

ASSESSMENT OF RISKS

Risk Factors for Acquiring HTLV-III/LAV Infection and Transmission. In adults and adolescents, HTLV-III/LAV is transmitted primarily through sexual contact (homosexual or heterosexual) and through parenteral exposure to infected blood or blood products. HTLV-III/LAV has been isolated from blood, semen, saliva, and tears but transmission has not been documented from saliva and tears. Adults at increased risk for acquiring HTLV-III/LAV include homosexual/bisexual men, intravenous drug abusers, persons transfused with contaminated blood or blood products, and sexual contacts of persons with HTLV-III/LAV infection or in groups at increased risk for infection.

The majority of infected children acquire the virus from their infected mothers in the perinatal period (*1-4*). In utero or intrapartum transmission are likely, and one child reported from Australia apparently acquired the virus postnatally, possibly from ingestion of breast milk (*5*). Children may also become infected through transfusion of blood or blood products that contain the virus. Seventy percent of the pediatric cases reported to CDC occurred among children whose parent had AIDS or was a member of a group at increased risk of acquiring HTLV-III/LAV infection; 20% of the cases occurred among children who had received blood or blood products; and for 10%, investigations are incomplete.

HTLV-III/LAV – Continued

Risk of Transmission in the School, Day-Care or Foster-Care Setting. None of the identified cases of HTLV-III/LAV infection in the United States are known to have been transmitted in the school, day-care, or foster-care setting or through other casual person-to-person contact. Other than the sexual partners of HTLV-III/LAV-infected patients and infants born to infected mothers, none of the family members of the over 12,000 AIDS patients reported to CDC have been reported to have AIDS. Six studies of family members of patients with HTLV-III/LAV infection have failed to demonstrate HTLV-III/LAV transmission to adults who were not sexual contacts of the infected patients or to older children who were not likely at risk from perinatal transmission (*6-11*).

Based on current evidence, casual person-to-person contact as would occur among schoolchildren appears to pose no risk. However, studies of the risk of transmission through contact between younger children and neurologically handicapped children who lack control of their body secretions are very limited. Based on experience with other communicable diseases, a theoretical potential for transmission would be greatest among these children. It should be emphasized that any theoretical transmission would most likely involve exposure of open skin lesions or mucous membranes to blood and possibly other body fluids of an infected person.

Risks to the Child with HTLV-III/LAV Infection. HTLV-III/LAV infection may result in immunodeficiency. Such children may have a greater risk of encountering infectious agents in a school or day-care setting than at home. Foster homes with multiple children may also increase the risk. In addition, younger children and neurologically handicapped children who may display behaviors such as mouthing of toys would be expected to be at greater risk for acquiring infections. Immunodepressed children are also at greater risk of suffering severe complications from such infections as chickenpox, cytomegalovirus, tuberculosis, herpes simplex, and measles. Assessment of the risk to the immunodepressed child is best made by the child's physician who is aware of the child's immune status. The risk of acquiring some infections, such as chickenpox, may be reduced by prompt use of specific immune globulin following a known exposure.

RECOMMENDATIONS

1. Decisions regarding the type of educational and care setting for HTLV-III/LAV-infected children should be based on the behavior, neurologic development, and physical condition of the child and the expected type of interaction with others in that setting. These decisions are best made using the team approach including the child's physician, public health personnel, the child's parent or guardian, and personnel associated with the proposed care or educational setting. In each case, risks and benefits to both the infected child and to others in the setting should be weighed.
2. For most infected school-aged children, the benefits of an unrestricted setting would outweigh the risks of their acquiring potentially harmful infections in the setting and the apparent nonexistent risk of transmission of HTLV-III/LAV. These children should be allowed to attend school and after-school day-care and to be placed in a foster home in an unrestricted setting.
3. For the infected preschool-aged child and for some neurologically handicapped children who lack control of their body secretions or who display behavior, such as biting, and those children who have uncoverable, oozing lesions, a more restricted environment is advisable until more is known about transmission in these settings. Children infected with HTLV-III/LAV should be cared for and educated in settings that minimize exposure of other children to blood or body fluids.

HTLV-III/LAV — Continued

4. Care involving exposure to the infected child's body fluids and excrement, such as feeding and diaper changing, should be performed by persons who are aware of the child's HTLV-III/LAV infection and the modes of possible transmission. In any setting involving an HTLV-III/LAV-infected person, good handwashing after exposure to blood and body fluids and before caring for another child should be observed, and gloves should be worn if open lesions are present on the caretaker's hands. Any open lesions on the infected person should also be covered.
5. Because other infections in addition to HTLV-III/LAV can be present in blood or body fluids, all schools and day-care facilities, regardless of whether children with HTLV-III/LAV infection are attending, should adopt routine procedures for handling blood or body fluids. Soiled surfaces should be promptly cleaned with disinfectants, such as household bleach (diluted 1 part bleach to 10 parts water). Disposable towels or tissues should be used whenever possible, and mops should be rinsed in the disinfectant. Those who are cleaning should avoid exposure of open skin lesions or mucous membranes to the blood or body fluids.
6. The hygienic practices of children with HTLV-III/LAV infection may improve as the child matures. Alternatively, the hygienic practices may deteriorate if the child's condition worsens. Evaluation to assess the need for a restricted environment should be performed regularly.
7. Physicians caring for children born to mothers with AIDS or at increased risk of acquiring HTLV-III/LAV infection should consider testing the children for evidence of HTLV-III/LAV infection for medical reasons. For example, vaccination of infected children with live virus vaccines, such as the measles-mumps-rubella vaccine (MMR), may be hazardous. These children also need to be followed closely for problems with growth and development and given prompt and aggressive therapy for infections and exposure to potentially lethal infections, such as varicella. In the event that an antiviral agent or other therapy for HTLV-III/LAV infection becomes available, these children should be considered for such therapy. Knowledge that a child is infected will allow parents and other caretakers to take precautions when exposed to the blood and body fluids of the child.
8. Adoption and foster-care agencies should consider adding HTLV-III/LAV screening to their routine medical evaluations of children at increased risk of infection before placement in the foster or adoptive home, since these parents must make decisions regarding the medical care of the child and must consider the possible social and psychological effects on their families.
9. Mandatory screening as a condition for school entry is not warranted based on available data.
10. Persons involved in the care and education of HTLV-III/LAV-infected children should respect the child's right to privacy, including maintaining confidential records. The number of personnel who are aware of the child's condition should be kept at a minimum needed to assure proper care of the child and to detect situations where the potential for transmission may increase (e.g., bleeding injury).
11. All educational and public health departments, regardless of whether HTLV-III/LAV-infected children are involved, are strongly encouraged to inform parents, children, and educators regarding HTLV-III/LAV and its transmission. Such education would greatly assist efforts to provide the best care and education for infected children while minimizing the risk of transmission to others.

HTLV-III/LAV – Continued

References

1. Scott GB, Buck BE, Leterman JG, Bloom FL, Parks WP. Acquired immunodeficiency syndrome in infants. N Engl J Med 1984;310:76-81.
2. Thomas PA, Jaffe HW, Spira TJ, Reiss R, Guerrero IC, Auerbach D. Unexplained immunodeficiency in children. A surveillance report. JAMA 1984;252:639-44.
3. Rubinstein A, Sicklick M, Gupta A, et al. Acquired immunodeficiency with reversed T4/T8 ratios in infants born to promiscuous and drug-addicted mothers. JAMA 1983;249:2350-6.
4. Oleske J, Minnefor A, Cooper R Jr, et al. Immune deficiency syndrome in children. JAMA 1983;249:2345-9.
5. Ziegler JB, Cooper DA, Johnson RO, Gold J. Postnatal transmission of AIDS-associated retrovirus from mother to infant. Lancet 1985;i:896-8.
6. CDC. Unpublished data.
7. Kaplan JE, Oleske JM, Getchell JP, et al. Evidence against transmission of HTLV-III/LAV in families of children with AIDS. Pediatric Infectious Disease (in press).
8. Lewin EB, Zack R, Ayodele A. Communicability of AIDS in a foster care setting. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.
9. Thomas PA, Lubin K, Enlow RW, Getchell J. Comparison of HTLV-III serology, T-cell levels, and general health status of children whose mothers have AIDS with children of healthy inner city mothers in New York. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.
10. Fischl MA, Dickinson G, Scott G, Klimas N, Fletcher M, Parks W. Evaluation of household contacts of adult patients with the acquired immunodeficiency syndrome. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.
11. Friedland GH, Saltzman BR, Rogers MF, et al. Lack of household transmission of HTLV-III infection. EIS Conference, Atlanta, Georgia, April 1985.

RESOLUTION ACCEPTING THE REPORT ON THE CONTROL OF PERINATALLY TRANSMITTED HTLV-III/LAV ASSOCIATED VIRUS INFECTION AND CARE OF INFECTED MOTHERS, INFANTS AND PRE-SCHOOL AGED CHILDREN AND ADOPTING THE RECOMMENDATIONS AS OFFICIAL GUIDELINES FOR THE DEPARTMENT OF PUBLIC HEALTH.

Whereas, the Department of Public Health has issued a report which contains information and recommendations on perinatal HTLV-III/LAV infection and pediatric AIDS which were developed and compiled by a task force of the Department of Public Health; and

Whereas, the task force included representatives of the departments of obstetrics and gynecology, medicine and pediatrics, and the AIDS Activities Unit, San Francisco General Hospital, University of California, the San Francisco Medical Society; the American Academy of Pediatrics; the San Francisco Gynecologic Society, and the Department of Social Services, the City Attorney's Office, and the Juvenile Court of San Francisco; and

Whereas, the report contains recommendations on risk reduction education, laboratory testing procedures; pre-conception recommendations; identification of infected women; care of infected women and intravenous drug using mothers; and also contains recommendations on the identification of exposed infants and the care of exposed and infected infants and children which will protect and promote public health; and

Whereas, the members of the Health Commission support the recommendations made in the report; now therefore be it

Resolved; That the Health Commission accepts the report on policies regarding the control of the perinatally transmitted HTLV-III/LAV infection and the care of infected mothers, infants and pre-school aged children, and adopts the recommendations contained therein as guidelines for the Department of Public Health.

DRAFT

Guidelines for the Control of
Human Immunodeficiency Virus Infection
in Adolescents

Adolescent AIDS Task Force
Perinatal and Pediatric AIDS Advisory Committee
Department of Public Health
City and County of San Francisco

November 18, 1986

The information and recommendations contained in this report were developed and compiled by the Adolescent AIDS Task Force, a task force of the Perinatal and Pediatric AIDS Advisory Committee of the Department of Public Health, City and County of San Francisco. It included representatives from the Adolescent Medicine Divisions of the Departments of Pediatics of San Francisco General Hospital and the University of California, San Francisco; the Bureau of Family Health, the Bureau of Communicable Disease Control, and Community Substance Abuse Services, San Francisco Department of Public Health; the Medical and Juvenile Justice Staff of Youth Guidance Center, San Francisco's juvenile detention facility; community agencies serving sexual minority and homeless adolescents; the San Francisco AIDS Foundation; the AIDS Health Project; and the National Center for Youth Law. These recommendations were developed in response to requests from juvenile justice staff and other agencies involved in residential placements of adolescents for guidelines for antibody testing and placement of youth at risk for or infected with human immunodeficiency virus (HIV). This includes adolescents with Centers for Disease Control (CDC)-defined acquired immunodeficiency syndrome (AIDS), those with lesser clinical manifestations of HIV infection such as AIDS-related complex (ARC), and those with asymptomatic infection.

The recommendations which follow apply to all adolescents known to be infected or at risk of being infected with HIV. They are designed to supplement previously published guidelines for the control of perinatally transmitted HIV infection (1,2) and for the education of HIV-infected children (3,4).

BACKGROUND

HIV Infection in the Adolescent Age Group.

As of May 16, 1986, 86 cases of AIDS in persons 13 to 19 years old had been reported in the United States. This represents approximately 0.4 percent of all reported AIDS cases. The median age of these patients was 19 years old, and 79 percent were 17 years old or older. Thirty-two percent were white, 42 percent black, and 20 percent Hispanic. They were reported from 23 states, the District of Columbia, and Puerto Rico; 10 (12 percent) were from California. Forty-nine percent were homosexual or bisexual males, 27 percent had received infected blood or blood products, 9 percent had been infected through heterosexual contact, and 7 percent were heterosexual intravenous drug users (CDC, unpublished data). In San Francisco, as of the same date, there had been 4 cases of AIDS reported in adolescents. All were 17 years old or older; two were white, one black, and one Hispanic. Three were homosexual or bisexual males, and one was a hemophiliac. (San Francisco Department of Public Health, unpublished data) Thus, both nationally and locally adolescent AIDS and, by inference, all adolescent HIV infection are primarily diseases of older gay male adolescents and hemophiliacs, with a higher proportion of non-whites than compared to AIDS in older persons.

HIV Transmission in Households

None of the identified cases of HIV infection in the United States are known to have been transmitted in school, day care, or foster care settings, or through other casual person-to-person contact (4). Other than sexual partners of HIV-infected patients, infants born to infected mothers, or two cases involving nonparenteral transmission of HIV from a patients to person providing extended nursing care (5,6), none of the family members of the over 23,000 AIDS patients reported to CDC have developed AIDS. Eleven studies of family members of patients with HIV infection have failed to demonstrate HIV transmission to adults who are not sexual contacts of the infected patients or to children who have not already been infected perinatally (7-17). However, if casual person-to-person transmission of HIV infection does exist, it should theoretically be greatest among young children. This theoretical transmission would most likely involve exposure of open skin lesions or mucous membranes to blood and possibly other body fluids of an infected person. We emphasize that there is no evidence of this type of transmission occurring in any setting.

HIV Transmission in Health Care Settings

Transmission of HIV in hospitals and other health care settings has been evaluated in 5 separate studies involving 1,498 health care workers (18-23). Six hundred sixty-six (45%) of these health care workers had direct parenteral (needlestick or cut) or mucous membrane exposure to patients with AIDS or HIV infection, primarily to blood. Twenty-six were found to be seropositive when first tested; all but 3 belonged to groups at increased risk for AIDS (18). One of these 3 was tested anonymously and epidemiologic information was unavailable. Of the 2 for whom information was available, both were reported as probable occupationally related HIV infection (18), but neither had a preexposusre nor an early postexposure serum to conclusively determine the onset of illness. In addition, there are case reports of a nurse who seroconverted following accidental parenteral exposure to a needle contaminated with blood from an AIDS patient (24), of a mother who seroconverted following extensive prolonged mucous membrane exposure to blood from her child with transfusion-associated AIDS (5), and of a woman providing home nursing care who developed AIDS following prolonged and frequent percutaneous exposure to an AIDS patient (6). On the basis of these and other data, it has been concluded that needle stick-associated transmission of HIV occurs extremely infrequently in health care settings, certainly much less so than hepatitis B (25), probably in less than 0.5% of needle sticks involving seropositive patients (26), and, therefore, infection control recommendations have focused on minimizing needle stick injuries (26,27).

Existing Guideline for Correctional Settings

National recommendations have not yet been made regarding prevention of HIV infection in correctional settings. In a survey of 50 state correctional departments and 33 large city and county jail systems, none of the 8 cases of AIDS in correctional staff was related to inmate contact (28). The great majority of AIDS patients in prisons and jails were intravenous drug users. No cases of HIV infection were known to have been acquired in detention. Eighty-three percent of these institutions had educational programs for staff and inmates, and the large majority had adopted conservative approaches to testing with 88% of the state and 79% of the city and county facilities limiting testing to diagnosis of symptomatic inmates or testing at the request of inmates, or not doing any testing. Only 6 state and 7 city and county institutions did routine testing. Therefore, in large part, correctional institutions have opted for limited testing despite the fact that many deal with large numbers of inmates in well recognized high risk groups.

Concerns Regarding the Legal Rights of Minors

California statutes guarantee minors the right to obtain services for the diagnosis and treatment of sexually-transmitted diseases (25) and for the provision of services related to pregnancy, pregnancy diagnosis (30), and chemical dependency (31) without parental consent. California law also provides minors with the same rights to confidentiality as adults seeking such services (32). Chapter 1.11, Section 199.20 et_seq of the California Health and Safety Code (AB 403) requires informed written consent before serologic testing for the presence of HIV may be performed or test results may be disclosed. Current legal interpretation of the above statutes is that adolescents over age 12 have the same rights to consent and confidentiality in the area of HIV testing as do adults and do not require their parents consent to be tested. Thus, adolescents should not be tested without their written consent; and their test results should only be disclosed based on their written authorization.

RECOMMENDATIONS

Education

1. Adolescents_in_School_Settings. It is urgent that schools provide meaningful information about the modes of transmission and the risks of acquiring HIV infection to students, parents and teachers. The basic principles of health promotion and communicable disease prevention should be part of the K-12

curriculum. In addition, Family Life Education should begin in the sixth grade at the latest and should include units on sexual values and attitudes, as well as the prevention of sexually transmsitted diseases including HIV infection. Personnel responsible for teaching these units should be fully trained and certified to be competent in handling the sensitive issues raised by this subject area. Parents should be informed of the inclusion of this material in the curriculum and invited to review and comment on the contents. They should also, where possible, be provided with the opportunity to participate in informational meetings to address their concerns and answer their questions. In addition to previous recommendations regarding education (3), we recommend that the Board of Education develop and institute competency tests in the area of health education, including HIV and other communicable diseases, to guarantee that the material has been taught in an effective manner.

2. Homeless and Truant Adolescents. Public and private agencies serving these populations should develop educational materials and intervention strategies which can be integrated into their current programs. Attempts should be made to reach homeless adolescents in areas of the city not currently served by existing providers. All personnel involved in these programs should be given adequate information and training in the prevention of and identification of those at risk for HIV infection as well as techiques for intervening with adolescents in the area of sexual

behavior and intravenous drug use. Safe sex practices should be encouraged in all adolescents seen regardless of sexual orientation, drug use, or other risk indicators.

3. Outpatient Services for At-Risk Adolescents. This group includes adolescents involved in drug, alcohol, and mental health programs and adolescents receiving family planning services, sexually transmitted disease treatment, and specialized services for sexual minorities. We recommend that the same recommendations made for homeless and truant adolescents (Section 2) be followed for this group.

4. Youth in Residential Settings. Due to the special circumstances in these facilities, we recommend a comprehensive approach similar to that for the schools, i.e., thorough education of staff in the areas of sexuality, sexually transmitted diseases, and HIV prevention including safe sex guidelines; general infection control guidelines; materials and group sessions for the residents; and education of parents where possible.

Testing Recommendations

In general we believe that testing for the presence of anti-HIV antibody is not useful for adolescents and recommend that it not be routinely advocated or required. Occasionally, antibody testing may be appropriate in evaluating adolescent patients with unexplained adenopathy or other signs and symptoms of HIV infection. In these rare instances, testing should be conducted in a medical specialty clinic experienced in the diagnosis and treatment of HIV infection. In other instances, anonymous testing at alternative test sites may be appropriate as a health educational experience for certain highly motivated adolescents. In any event, this testing must be voluntary and should not be conducted while the adolescent is in detention. Confidentiality requirements should be strictly observed with respect to any testing of adolescents.

1. Non-Residential Settings

a. Schools. Previously published guidelines developed by the Department of Public Health for the San Francisco Unified School District recommend that (a) widespread school-based educational programs be implemented for students, parents, and teachers; (b) there be no mandatory HIV antibody testing for school staff; (c) placement decisions regarding students known to be infected with HIV be reviewed by a joint committee of the Department of Public Health and the San Francisco Unified School District; (d) strict confidentiality be maintained; and (e) uniform disinfection procedures by adopted (3).

b. Pregnant Adolescents. Previously published guidelines developed by the Department of Public Health recommended that HIV antibody testing be conducted on a confidential basis by the prenatal care provider in the first trimester only for women who are at risk of having been exposed to HIV infection (1).

2. Residential Settings. Residential settings include foster care, group homes, shelters for homeless adolescents, and juvenile justice and mental health facilities. All adolescents entering residential setting should have a complete medical evaluation upon admission. If the adolescent is determined to be at-risk for HIV infection, testing can be suggested by the medical provider according to general guidelines stated above. We do not recommend mandatory testing, regardless of risk status due to the low incidence of seropositivity in this population.

There is no reason to require testing of staff in these settings. All residential settings need to insure that they have updated infection control guideline stressing uniform disinfection procedures for body fluid spills. All staff need to be educated about the techniques involved in implementing these guidelines.

Recommendations for Youth Known to be Infected with HIV

1. Non-Residential Settings. We recommend that HIV-infected adolescents have no restrictions on access to educational or other treatment programs except when their health provider recommends such restrictions to protect them from exposure to infection. Previously published guidelines for the education of children

infected with HIV provide for a case review for any infected student enrolling in the schools (3).

2. Residential Settings

a. Adolescents in Detention. All adolescents entering detention should have a thorough medical evaluation. A specially-designated on-site physician should make the determination as to whether the adolescents can be housed in a routine setting or whether there needs to be a more protected environment. Routine isolation is not indicated. Regardless of the placement decision, the right of the adolescent to confidentiality must be maintained. The fact that an adolescent is infected should not be disclosed to anyone (including other detained adolescent or probationary counseling or residential staff) except for medical staff involved in his or her direct care. As mentioned previously, staff should follow strict infection control procedures in these settings whether or not these facilities are housing HIV-infected individuals.

b. Youth in Other Residential Facilities. There is no reason to exclude asymptomatic HIV infected adolescents from any residential setting. A medical review should be done prior to placement to determine any special needs. Confidentiality should be carefully maintained. Disclosure to social service, legal, or probation personnel should not occur unless, as determined in the medical review, such disclosure is necessary for the protection of the adolescent or others with whom he or she may have contact. Disclosure to anyone other than the adolescent medical provider should occur only with the written consent of the adolescent or court order when deemed medically necessary. Obviously adolescents who are clinically ill require special care, and this will have to be arranged on a case-by-case basis.

Special counseling should be available for infected adolescents in all residential settings. This should include psychosocial support as well as coordination of services which the adolescent currently needs or will need to cope with the disease.

Recommendations for Asymptomatic Adolescents with High Risk Behaviors Whose Antibody Status is Unknown

Intensive educational efforts should be targeted to this group and their service providers. As long as the incidence of HIV infection and clinical AIDS remains low in adolescents, there should not be any restrictions on residential placements and no routine testing including correctional settings. Adolescents who have been counseled and request testing should be referred to anonymous test sites.

CONCLUSIONS

These are interim guidelines which will need to be reviewed as more information becomes available on the incidence and natural history of HIV infection in adolescents. We emphasize that the prevalence of HIV infection among adolescents in San Francisco is low and that there is no evidence supporting HIV transmission among adolescents not involved in sexual contact with infected partners, not sharing needles, and not exposed to blood or blood products. We conclude that routine testing for HIV infection should not be conducted in any group of adolescents at this time.

1. San Francisco Department of Public Health. Guidelines for control of perinatally transmitted human T-lymphotropic virus-type III/lymphadenopathy-associated virus infection and care of infected mothers, infants, and children. San Francisco Epidemiologic Bulletin 1986; 2(suppl 1): 1S-16S.
2. CDC. Recommendations for assisting in the prevention of perinatal transmission of human T-lymphotropic virus type III/lymphadenopathy-associated virus and acquired immunodeficiency syndrome. MMWR 1985; 34:721-6, 731-2.
3. San Francisco Department of Public Health. Education of children infected with human immunodeficiency virus. San Francisco Epidemiologic Bulletin (in press).
4. CDC. Education and foster care of children infected with human T-lymphotropic virus type III/lymphodenopathy-associated virus MMWR 1985; 34:517-21.
5. CDC. Apparent transmission of human T-lymphotropic virus type

III/lymphadenopathy-associated virus from a child to a mother providing health care. MMWR 1986; 35:76-79.

6. Grint P, McEvoy M. Two associated cases of the acquired immune deficiency syndrome (AIDS). *Communicable Disease Reports* 1985; 42:4.

7. Fischl MA, Dickinson GM, Scott GB, Klimas N, Fletcher MA, Parks W. Heterosexual and household transmission of the human T-lymphotropic virus type III. 2nd International Conference on Acquired Immunodeficiency Syndrome (AIDS), Paris, France, June 1986.

8. Friedland GH, Saltzman BR, Rogers MF, *et al*. Lack of transmission of HTLV-III/LAV infection ot household contacts of patients with AIDS or AIDS-related complex with oral candidiasis. *N Engl J Med* 1986; 314: 344-9.

9. Jason JM, McDougal JS, Lawrence DN, Kennedy MS, Hilgartner M, Evatt BL. Lymphadenopathy-associated virus (LAV) antibody and immune status of household contacts and sexual partners of persons with hemophilia. *JAMA* 1986; 255:212-15.

10. Kaplan JE, Oleske kJM, Getchell JP, *et al*. Evidence against transmission of HTLV-III/LAV in families of children with AIDS. *Pediatr Infect Dis* 1985; 4:468-71.

11. Lawrence DN, Jason JM, Bouhasin JD, *et al*. HTLV-III/LAV antibody status of spouses and household contacts assisting in home infusion of hemophilia patients. *Blood* 1985; 66:703.

12. Lewin EB, Zack R, Ayodele A. Communicability of AIDS in a foster care setting. International Conference on Acquired

Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.

13. Peterman TA, Stoneburner RL, Allen JR. Risk of HTLV-III/LAV transmission to household contacts of persons with transfusion-associated HTLV-III/LAv infection. 2nd International Conference on Acquired Immunodeficiency Syndrome (AIDS), Paris, France, June 1986.

14. Redfield RR, Markham PD, Salahuddin SZ, *et al*. Frequent transmission of HTLV-III among spouses of patients with AIDS-related complex (ARC) and acquired immunodeficiency syndrome (AIDS): a family study. *JAMA* 1985; 253:1571-3.

15. Rogers MF, White CR, Sanders R, *et al*. Can children transmit human T-lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV) infection? 2nd International Conference on Acquired Immunodeficiency Syndrome (AIDS), Paris, France, June 1986.

16. Saltzman BR, Friedland GH, Rogers MF, *et al*. Lack of household transmission of HTLV-III/LAV infection. 2nd International Conference on Acquired Immunodeficiency Syndrome (AIS), Paris, France, June 1986.

17. Thomas PA, Lubin K, Enlow RW, *et al*. Comparison of HTLV-III serology, T-cell levels, and general health status of children whose mothers have AIDS with children of healthy inner city mothers in New York. International Conference on Acquired Immunodeficiency Syndrome (AIDS), Atlanta, Georgia, April 1985.

18. CDC. Update: evaluation of human T-lymphotropic virus type III/lymphadenopahty-associated virus infection in health-care

personnel - United States. MMWR ;1985; 34:575-8.

19. Hirsch MS, Wormser GP, Schooley RT, et al. Risk of nosocomial infection with human T-cell lymphotropic virus III (HTLV-III). N Engl J Med 1985; 312:1-4.

20. CDC. Update: prospective evaluation of health-care workers exposed via the parenteral or mucous-membrane route to blood or body fluids from patients with acquired immunodeficiency syndrome-United States. MMWR 1985; 34:101-3.

21. McCray E. The Cooperative Needlestick Study Group. Occupational risk of the acquired immunodeficiency syndrome among health care workers. N Engl J Med 1986;314:1127-32.

22. Gerberding JL, Moss AR, Brykant CE, Levy J, Sande MA. Risk of acquired immune deficiency syndrome (AIDS) virus transmission to health care workers. 25th Interscience Conference on Antimicrobial Agents and Chemotherapy, Minneapolis, Minnesota, October, 1985.

23. Weiss SH, Saxinger WC, Rechtman D, et al. HTLV-III infection among health care mothers: association with needle-stick injuries. JAMA 1985; 254:2089-93.

24. Anonymous. Needlestick transmission of HTLV-III from a patient infected in Africa. Lancet 1984; 2:1376-7.

25. Gerberding JL, Hopewell PC, Kamingky LS, Sande MA. Transmission of hepatitis B without transmission of AIDS by accidental needlestick. N Engl J Med 1985; 312:56.

26. Sande MA. Transmission of AIDS: the case against casual contagion [editorial] N Engl J Med 1986; 314:380-2.

27. CDC. Recommendations for preventing transmission of infection

with human T-lymphotropic virus type III/lymphadenopathy-associated virus in the workplace. MMWR 1985;34:682-6,691-5.

28. CDC. Acquired immunodeficiency syndrome in correctional facilities: a report of the National Institue of Justice and the American Correctional Institute. MMWR 1986; 35:195-9.

29. Civil Code, Section 34.7.

30. Civil Code, Section 34.5.

31. Civil Code, Section 34.10.

32. For example, Civil Code, Section 56.11(c)(2); Health and Safety Code, Section 25252(a).

Chairman **Miller**. Thank you, Dr. Grossman.

I am going to ask the panel if they have any questions for you. Congressman Dellums.

Mr. **Dellums**. Yes. Doctor, you mentioned that you agree with me with respect to the issue of civil rights, but you specifically went to certain legislation passed by the state legislature that you thought prohibited the capacity to assist in this area. Would you elaborate on that and be a little more specific?

Dr. **Grossman**. If the obstetrician or the person who is dealing with the mother knows that the mother is HIV positive, in other words infected, he is prohibited from sharing that information with the delivery room nurses, who might be exposed.

While I firmly believe that AIDS is not transmitted by casual transmission, contact in the delivery rooms is not casual. Large amounts of body fluids and the placenta are all infected. So, the delivery room personnel need to be protected.

Furthermore, the person taking care of the baby needs to be informed that the baby is at risk because the medical management of the baby is different. So, maybe some legislation would be necessary, and I have discussed this with some members of the state legislature, to make adjustments in the case of prenatal AIDS.

Mr. **Dellums**. Thank you, sir.

Chairman **Miller**. Congresswoman Boxer?

Mrs. **Boxer**. If a woman has AIDS or ARC, is it definite that the child would have AIDS or ARC?

Dr. **Grossman**. I am glad you asked that question. If a woman has AIDS, if she is HIV positive, her antibodies will be transmitted to the baby. So, when the baby is first born, the baby is antibody positive. There is no way of knowing immediately at birth whether the baby is or is not infected, until we get six or eight months down the line.

Approximately fifty percent, just to give you a round number, of these babies will be infected.

Mrs. **Boxer**. Fifty percent.

Dr. **Grossman**. Fifty percent.

Mrs. **Boxer**. Then, do you feel we ought to move toward requiring a blood test for marriage to test for AIDS?

Dr. **Grossman**. Well, I have given this quite a bit of thought. My own personal position is that with the current prevalence of AIDS, we should strongly encourage it but not yet require it. As the disease spreads, I may change my view.

Mrs. **Boxer**. Thank you.

Chairman **Miller**. Congressman Stark?

Mr. **Stark**. Doctor, with limited experience thus far, what can you project, hopefully not the worst case, but what you anticipate may happen in the future? What do you see for general hospitals in the medical care delivery system, and then children's hospitals in communities where we are fortunate enough to have them? What do you see as the impact just on financing and on the system in general. Do you have to build special wards? Are there going to be great impacts or is it just an expansion of the present system?

Dr. **Grossman**. No. I think that if the predictions hold true, and I believe they will, we have to think about separate systems because the impact on the present system is going to be absolutely enormous.

Mr. **Stark**. Actually separate hospitals?

Dr. **Grossman**. I think either separate hospitals—we use to have communicable disease hospitals in the past, and separate facilities, and not only acute facilities are needed, convalescent facilities will also be needed.

San Francisco, as you probably know, has probably the most enlightened system in the country, and it is the most cost-effective.

Mr. **Stark**. Children's hospitals too?

Dr. **Grossman**. Not yet for children. But the system for adults is absolutely straining. It is absolutely at its limits.

Chairman **Miller**. When you talk about separate systems, are you talking about separate children's facilities?

Dr. **Grossman**. I am now talking about adult AIDS. The impact of adult AIDS, as we foresee it today will be enormous because we have a pretty good idea of numbers. It is probably greater than the impact of children's AIDS because the numbers are greater. The numbers of people alive who are now infected is, as you know, very, very high. We expect a large percentage of them will come down with the disease.

Children's numbers will always be smaller, I think, because infected children do not live very long. So, the number of children who are alive is going to be smaller. There is a development that could occur which will affect both children and adults if successful drugs are found to control the virus. It is possible that we will see large numbers of people who will be alive who will not progress, but who will be neurologically affected because the virus affects the brain in most instances, producing a disease like Alzheimer's.

These individuals, adults and children, will also require care, probably some kind of custodial care. I think the costs are going to be phenomenal. For children, I think the biggest problem today that I see is finding a place for them. It is difficult to find foster homes, and adoptive homes, and you may have read that one major hospital opened a ward for such children. That is no place for a child to live. There is not much emotional development going to occur in a hospital ward.

So, we need to think about how we can place these children, one of the other speakers will address that question.

Chairman **Miller**. Let me ask, is it realistic—it may be realistic because that is what the problem is going to require, but as you anticipate how you move into a system where you may need separate facilities, from a public policy point of view, how do you bring that about?

You know that we have private hospitals and public hospitals, and they are all run under different systems. Is somebody going to designate those, are we going to commandeer them from the Federal Government, to designate those facilities or are you . . .

Dr. **Grossman**. Well, I think what Congress does about costs is going to make a great deal of difference. Today, in our hospital, San Francisco General, even though every AIDS patient is eligible for MediCal and Medicaid, we lose $50 on every patient because of the way the reimbursements are set.

The City of San Francisco subsidizes the extra $50. The more patients we have, the more we lose. You know, this cannot go on. So, I think if reimbursements are adequate because the cost is high, the private sector may become interested.

The sort of things we have talked about in San Francisco, and it is just talk, I want to emphasize that, no decisions have yet been made, is motivating some of the private sector hospitals who have a lot of empty beds to open major services for AIDS patients. At the moment the only one who has those is San Francisco General, where I work.

The other possibility we talked about is asking the Federal Government if it is interested in reopening the U.S. Public Health hospital in San Francisco. It was closed some time ago, and is now under the Department of Defense. Again, just talk. That is one of the options.

Chairman **Miller**. I assume in that context we also have to confront the civil rights issue of separate facilities.

Dr. **Grossman**. Probably would, but if the numbers come to a point, there may be

Chairman **Miller**. No options. I understand that.

Mr. **Stark**. Doctor, did you say or did I interpret what you said to mean that even if we find some way to kill the virus, that after a certain period of time, their mental capacity will be so diminished from having AIDS till we arrest it, then we are going to have a group of disabled people who are cured? Is that—Dr. Grossman. Yes. You have caught my drift correctly. One of the first effective drugs is AZT. Again, I am not talking about children now. AZT is now being used. AZT prolongs life but it doesn't cure anybody. So, the people seem to live twice as long, which means you have twice as many patients to care for at any given time, and it costs twice as much, and the drugs are expensive, and, yet, the outcome in the end may be the same.

So, that is one issue. The other issue is that the brain is almost always affected—the virus destroys brain tissue. So, if you stop the progression of the disease, at least for X number of years, there is going to be a significant number of individuals whose neurological disease will require care, serious neurological disease, both adults and children.

One person writing about AIDS indicated that AIDS victims also faced poverty in that we are talking somewhere in the neighborhood of $114,000 per case. Is that figure something that you have had experience with or do you have any different kinds of figures for the amount of costs?

Dr. **Grossman**. I do not have that figure at all, Congressman. Since we are talking about children, let me point out that many of these children are born to mothers who have AIDS themselves. So, (a) they are ill and unable to care for the baby; (b) many of them are dead as the child grows up, so there is no mother, and the family unit is broken up quite often.

As far as adults are concerned, San Francisco's costs have been lower, but they are rising, and the cost of drugs is very high. I do not have a number for you, but it is very high.

Chairman **Miller**. One of the things that got me to thinking about this hearing was testimony from some of the people in

Newark who tried to get this committee, along with Congressman Waxman's committee, to visualize the idea of the dying parent trying to take care of the dying child. We had to ask ourselves what kind of facilities we envisioned those people living in, especially since a majority of the parents were still drug dependent. That is what they are confronting in Newark; there are absolutely no facilities—you are starting to turn hospitals or public facilities into communes so you can try to keep some semblance of this together. Of course, in other instances, the parent has other children at home, and it is just a total collapse.

This is one of the things that we hope to be able to explore. This is not going to be the last hearing on the subject, but there is just a total collapse in terms of the support system. It is non-existent for a number of these parents, either because they are also dying or they have other children, and we have just not matched the support systems with the problems, according to those who are working with it on the East Coast, where I think it is somewhat more advanced than we are seeing here so far.

So, I just ask the members to keep that in mind. Here we are with the first witness and we are talking about an entirely different health system than we have, an entirely different social support system, an entirely different family support system, and an entirely different maintenance system for disabled people, if we are successful, as we partially think we can be.

Welcome to the hearing. Welcome to the Children's Committee. How come we never have nice subjects on this committee? So, that is the challenge.

Thank you very much, Dr. Grossman.

Dr. **Grossman**. Thank you. I am sorry I have to leave.

Chairman **Miller**. Next, we will hear from Dr. Benjamin.

STATEMENT OF DR. ROBERT BENJAMIN, M.P.H., CHIEF, BUREAU OF COMMUNICABLE DISEASES, ALAMEDA COUNTY DEPARTMENT OF COMMUNITY HEALTH SERVICES, OAKLAND, CA

Dr. **Benjamin**. Good morning.

Many of the more clinical points that I wanted to talk about have already been very adequately covered by Dr. Grossman. What I would like to do, I think, is to go over very briefly our local situation here in this county to give you some idea of what is going on here, and a little bit more generically in the Bay Area.

In my testimony, I started with a more global discussion, and I think there is no need to reiterate that with you all.

In Alameda County, the number of cases that we have seen so far is 340. Now, while this does not seem like very much compared to what New York and San Francisco are seeing, if you put this on a national scale, this gives us as many cases as the state of Connecticut, and this is just one county.

Here, in this county, we have the advantage of being able to see the future by looking west. We see very clearly what has gone on in San Francisco, and those of us who are into long-range planning, and this is something that I will get to in a few minutes, we see very clearly that that is what is absolutely mandatory in order to prepare for what we see as coming.

Projections that we have made state that by 1990, we in this county will have as many cases as San Francisco now has. So, we have to prepare for that, and that is assuming, that is assuming that there is no further new infection. That is based on people who have already been infected.

Within our community of cases, eighty-one percent are gay or bisexual men, and about eight percent are IV drug users. We are seeing a slow increase in the number of heterosexuals. Right now, it is about 1.2 percent in terms of cases, and I think we can fairly add to that another two or three percent of those individuals who are now classed as new identifiable risk. They do not know how they got it, but they are active heterosexuals.

While we here in Alameda County have not yet seen any reported cases of pediatric AIDS, if there were a definition of pediatric ARC—I know of at least five cases that would be reported if such a condition were reportable.

No need to bore you with statistics relating IV drug use to vertical transmission. So, I will not go into that.

We have done some very interesting studies beginning with confidential testing in our methadone maintenance clinics, and what we have come up with is about a twelve percent seropositivity.

In this county, we have an estimated 20,000, give or take some, IV substance abusers. That is not only opiates, but other IV substances. This presents a very clear problem in terms of perinatal transmission.

Right now, and if we translate that into numbers, twelve percent of our estimated IV drug users comes up with about 2,400 infected individuals in that population alone. Right now, the CDC's

Chairman **Miller**. You are talking currently?

Dr. **Benjamin**. Yes. Right now. Actually, the study that we did was nine months ago.

Right now, the CDC is estimating somewhere around a million and a half to two million Americans already infected. The way they derive, as I understand it, those numbers is to take the number of actual cases, make some stab at the attack rate, and the attack rate is defined as those people who will develop—of those people who are infected, how many will develop the disease itself over time, and right now they are estimating it at about twenty-five percent, and I think most of us in the field believe that this is unrealistically low.

So, what was needed, we felt—I have a bit of a different talk prepared, but Dr. Grossman has done a lot of the groundwork. In this country, most of the general population firmly believes that this is a disease of those other people, and it is vitally necessary for us to get their attention and to get them to believe that if they are heterosexually active outside of monogamous relationships, there is some risk and they, indeed, could be at risk.

We tried, we struggled very hard with how to do such a feat. A very interesting study was done in San Francisco. There was a telephone survey, and they had lots of problems with telephone surveys, but what they did was they talked to heterosexuals who admitted over the phone having two or more sex partners, and what they found was forty percent of those people in San Francisco, which is a town that ought to know better, were practicing high-risk sexual behavior.

How can we get their attention? What we decided to do was a blind seroprevalent study, and that was the one that Dr. Grossman alluded to. For your information, let me sort of explain what a blind seroprevalent study is.

What we did was we took bloods that had been drawn at our V.D. clinics and our pre-marital test sites. They were drawn for some other purpose. They were drawn for syphilis testing, and after the testing that the blood was drawn for, was done, and just prior to the disposal of the bloods, we removed identifiers. We took names off.

What went on the tubes of blood were only age, sex, and what type of clinic site, not which sites specifically, but whether this was blood from a V.D. clinic or from a pre-marital testing site, and then we decided to look at what is the prevalence of. That is how we decided to look at it. What is the prevalence of the virus in the general population.

What we found looking at our V.D. clinic sample was overall 2.7 percent positivity. Now, we know that we see a fairly large——

Mrs. **Boxer**. Could you say that one more time, the number?

Dr. **Benjamin**. Within our V.D. clinics, we found 2.7 percent positive, both sexes, but because we know that we serve a fairly large number of both gay and bi-sexual men, what we decided to do was discard results or ignore results on bloods from men and look only at women. That way we could be certain that what we were looking at was a population other than gay or bi-sexual men.

What we found is a little bit alarming. Now, I have to state that because we were not funded to do this study, that there were also some questions about whether or not such a study in this state at that time was even legal, we kept it small.

Chairman **Miller**. Just a little.

Dr. **Benjamin**. Mind you, having worked on the development of AB-488, the legislation which funded the establishment of alternative test sites in this state, and having followed very closely its companion bill, AB-403, by Assemblyman Agnos, I had some very good idea of what the intent of that bill was, and I felt very strongly that this was not in conflict with that bill; otherwise, I never would have done it, but there was still some question.

What we found in our pre-marital testing sites and in our bloods from V.D. sites was that in women, we found a half percent positivity. Now, this does not seem very high, but what it translates into is about one in 200.

Now, it could—because we had no identifying information about these people, they could well all have been IV drug users. We do not know. We know that they were not gay or bi-sexual men. What we do know about these women is that they were sexually active or were about to be sexually active because of the nature of the test sites, and this is where this data is very important in terms of making projections about the spread of the disease and the population in general as well as vertical transmission to potential offspring.

Now, that information in and of itself is very important, but I think what was even more important and more revealing was the reaction of the general public to that information when it came out. A most outstanding thing happened.

The numbers of people presenting voluntarily to our alternate anonymous test sites in all of the counties in the Bay area, our county specifically, doubled, almost tripled, and the number and the type of people presenting changed dramatically.

In our county, prior to release of this study, about ten or fifteen percent of the people presenting for testing voluntarily were heterosexual. Now, we are running sixty to seventy percent. Similar shifts were found in San Francisco, Marin, Salerno, Contra Costa, other counties.

What this says is that this type of study, a blind seroprevalent study, has great utility, not only in understanding the rate of penetration of this virus into the general community, but as an educational tool for the general public, which they understood that all of a sudden, I mean, it just clobbered them over the head.

This said to them, gee, maybe we could be at risk and, even more outstandingly, it motivated them to take some action. Now, whether or not this will be translated into taking the real action that is necessary for prevention and that is in the heterosexual community, those with multiple sex partners, proper use of condoms every time, remains to be seen.

These kinds of studies, blind seroprevalent studies, need to be done repeatedly. They are called point prevalent studies. So that at any point in time, we can tell about the spread of this virus in the community and we can tell each community, and the studies will reveal very different risks in each community.

In Alameda County, it means about one in 200 women in this small sample, and I am hoping that it may be less, but I do not see any reason to believe that it should be. it would be very different in San Francisco if we did this study. My guess is that there would be a higher prevalency, and if we did this study in some of the rural counties, a much lower prevalency.

That brings me to prevention. The message here, I think, is very, very simple. I have not heard it stated loudly enough nor clearly enough nor simply enough. AIDS is a preventable disease. I hear we can stop AIDS now, we can hear all kinds—we hear all kinds of messages, but the one that I do not hear enough is this is a preventable disease.

Now, our object here is primary prevention, prevention of infection, not how to deal with people who are already infected and how maybe to prevent the disease from occurring.

Mr. Stark, your comments about costs are, I think, salient because I think the national experience has been that from time of diagnosis to time of death, it costs about a $140,000 per AIDS patient. In the Bay area, because of the support systems that we have been able to develop, the cost is much less; it is around $40,000.

I would much rather spend $100,000 and prevent five cases, even if that intervention—that is a very costly intervention to prevent only five cases. I would much rather do that than spend the same amount of money treating one. No question.

How to take this prevention message out into the public. My own feeling is that we need to make AIDS a women's health issue. This is not an abrogation of my responsibility as a male, but we have seen this work in terms of contraception. We need to empower women more fully to take responsibility over their own bodies, their own health, and responsibility for the health of their future and prospective offspring.

Women need to be empowered further to say no to their prospective sex partners. They need to feel comfortable in saying if you do not put that condom on, you are going to have to look for somebody else. Only if we can get that message across to women can we make a dent in the spread of this disease in the heterosexual population.

In terms of screenings, screening is another way of preventing disease in terms of its educational impact. I have already dealt with what happened here in the Bay area when we released the results of our tests. I think that attempts to mandate screening should be discouraged.

Our experience with pre-marital testing for syphilis has shown this to be a very costly way to go. It has been unproductive in that most marriage applicants have already been sexually active with their prospective partners. I think that the education needs to be offered at that time, that AIDS is sexually transmitted, and I think that screening should be offered but not mandated.

In this county, we are now putting in place protocols to offer confidential testing at all of our STD clinics, our pre-marital screening sites, and through every aspect of our perinatal programs, family planning, pregnancy testing, pre-natal.

I think planning is vital, and I am saying this not in a local context, but in a national context. I submitted at least to you all copies of our AIDS plan. AIDS is a disease with at least a five year incubation period. Any plan that does not take that into account and present itself as a five year plan is less than adequate, and I think every community in the United States needs to begin this kind of planning.

In terms of treatment, I am not sure I agree completely with what Dr. Grossman has said. I think that the nature of AIDS in the pediatric—pediatric AIDS is somewhat different from that in the adult. I think that because it is, at this point, the numbers are so low, I think we might think about, consider thinking about regional pediatric centers.

Within the Bay area, we now have four such places which could well qualify. U.C. San Francisco, Stanford, Children's Hospital, San Francisco, and Children's Hospital, the East Bay. I have already opened discussions with Children's Hospital here in Oakland. Their service area is outstanding. The East Bay, as far as their service attachment area is concerned, extends to Sacramento and as far as Nevada.

Chairman MILLER. If I could ask you to sum up a little bit, not to cut you off, but I am going to lose my panel in a half hour. You can come back. I would just like to let them hear the other people.

Dr. BENJAMIN. Actually, rather than go on ad nauseam, I will stop.

[Prepared statement of Robert Benjamin, M.D., follows:]

PREPARED STATEMENT OF ROBERT BENJAMIN, M.D., MPH, CHIEF, BUREAU OF COMMUNICABLE DISEASE CONTROL ALAMEDA COUNTY HEALTH CARE SERVICES AGENCY, OAKLAND, CA

Subject: AIDS and Young Children - Emerging Issues

A. Background - Dimensions of the Epidemic

There is no doubt but that we are now in the early phases of the most serious pandemic (world wide or global epidemic) of this century. Every nation which has looked for AIDS has identified cases. Some nations, predominantly those spread across the central parts of Africa, are reporting prevalence of infection in as high as 10% of their entire populations. The epidemiology of those infected is exhibiting wide regional and geographic variation.

In Africa, the disease appears equally prevalent among the sexes with a distribution of 1:1::male:female. The disease is clearly being transmitted through heterosexual contact and being further spread through transfusion of blood and the reuse of contaminated needles. Special survey studies have shown 10-13% of blood donors in Kinshasa, the capitol city of Zaire, are infected. Because the per capita expenditure for health in most developing countries is so low, it precludes the expenditures necessary to screen blood for HIV prior to transfusion. This mode of transmission, however, represents only a small fraction of the overwhelming sexual transmission. Further complicating the picture is the proven vertical transmission from infected women to newborn offspring with infection occurring in utero, at birth and/or during breast feeding. Globally, therefore, heterosexual transmission between adults and vertical transmission to the fetus represent the majority of the transmission taking place.

In the United States, as of December 1986, the CDC reported 29,003 cases. In the United States, while the modes of transmission remain the same, the epidemiology is a bit different with 74% of the cases being reported in homosexual/bisexual men (8% of whom also report IV drug use) and another 17% of cases reporting IV drug use as their only risk. Overall, the ratio of males to females is 13.7:1. Cases acquired through heterosexual contact account for 4% of the total.

Striking regional differences exist within the United States with gay/bisexual men making up the predominant caseload (97%) in San Francisco as compared to the State of New Jersey where IV drug use accounts for 52% and Newark, N.J., where an estimated 80% of their cases are heterosexual IV drug users.

When looking at ethnicity, differences between adult and pediatric cases are remarkable with 60% of adult cases White, 24% Black, and 14% Hispanic (38% people of color). Pediatric cases, however, are 20% White, 57% Black and 23% Hispanic (80% people of color) reflecting inner city IV drug use, heterosexual transmission between spouses and vertical transmission from infected mother.

Migration of the virus out of the gay population and into the general population is now occurring through bisexual activity, IV drug use, IV drug use in prostitutes, and other heterosexual activity involving multiple sex partners. As a result, regional differences in rates of new transmission of the HIV are being noted with a relative slowing of transmission in the gay communities of San Francisco, Los Angeles, and New York which have been the target of major educational interventions and an increase in the rates of new transmission in the IV drug using populations and in heterosexuals with large numbers of sex partners. Similarly, geographical distribution is shifting from urban to suburban and will eventually begin to appear in ever increasing numbers in the rural populations of America.

Locally, as of December 31, 1986, we have had a cumulative total of 328 AIDS cases reported in residents of Alameda County since we began surveillance in 1981. This ranks Alameda County fourth in the State after Los Angeles, San Francisco, and San Diego and gives us 1.2% of the nation's total caseload. If Alameda County were to be ranked in the CDC's listing by State, we would rank 16th in the nation, having only two cases fewer than Connecticut. (See CDC Surveillance Report, December 29, 1986, Appendix A).

Since 1981 we have seen the number of cases double unrelentingly every 12 months with 45% (149) of our cases diagnosed in 1986. Analysis by risk factor reveals 87% gay/bisexual men, 8% Hispanic and 4% Asian. Geographically, 76% of cases were in North County (55% in Oakland) and 24% in South County (See Appendix B for full statistical breakdown on Alameda County.)

B. Projections

In order to predict the future number of cases, multiple factors must be examined and taken into account. These have to do with current seroprevalence, estimates of the size of the populations at risk, and changes in other diseases with similar epidemiologic transmission patterns.

Studies done on sera from the general population, based on county studies as well as blood bank data, indicate a seropositivity range from 0.05% (blood banks) to 0.5% (general population). Similar studies undertaken in sexually transmitted disease clinics show a seroprevalence of 3% positive while the self selected-population presenting to the alternate test sites within Alameda County reveal 12% positivity.

Estimates of population at risk vary greatly but estimates of 30,000-51,000 gay/bisexual men and 18,000-21,000 IV substance users have been labeled as conservative with estimates for IV drug use often being several magnitudes larger.

Surrogate markers of behavior patterns provide useful information regarding risk of exposure to HIV. As general indicators of diseases transmitted sexually and by IV drug use, it is revealing to look at changes in incidence of hepatitis B, syphilis, and gonorrhea. Over the past two years, hepatitis B has increased 47%, gonorrhea, 14% and syphilis, 21%.

It is interesting to note that of all cases of infectious syphilis in 1983, 29.4% were among gay men as compared to 9.2% in 1986. This reveals a dramatic increase in syphilis among the heterosexual population. Similarly, a review of syphilis serologies of all women delivering at Highland Hospital (574) in the 9 month period between March and November of 1986 showed an average overall rate of positive serologic tests for syphilis of 12.2% with a range of 7% in June to 18% in November. These data do not bode well for assumptions suggesting that opportunities for new transmission of the HIV are decreasing--in point of fact, they indicate the opposite.

C. Seroprevalence Studies

A limited seroprevalence study done on attendees of one Methadone Maintenance Program within the county revealed an overall 12% seropositivity. While this prevalence is at this point in time still lower than is being experienced in most East Coast Cities, given our IV drug using population conservatively estimated at ±20,000, this would yield at least 2,400 infected, predominantly heterosexual IV drug users, many of whom are involved in the sex industry in order to support their drug habits.

In an effort to ascertain the extent to which this virus has penetrated into the general population, a blinded seroprevalence study was undertaken, utilizing bloods drawn from Alameda County's Sexually Transmitted Disease (STD) Clinics and Premarital Testing Sites. The assumption being that this sample would represent the general population of currently sexually active adults, presumably with multiple partners (STD clinics), and adults either currently, or about to be sexually active with presumably (although not necessarily) fewer partners (premarital sites).

Bloods were entered into the study after syphilis serologies were performed and just before they would normally have been discarded. Only sex and type of clinic (STD/PM) was placed on each tube of blood. Because all identifying information was removed after syphilis testing and before testing for HIV Antibody, no possibility existed for any test result to be linked to any individual, nor was it possible for any individual to identify his/her blood nor receive results of any testing. This "Blind" type of study was performed to assure anonymity and confidentiality.

Because we know that our STD clinics serve a sizeable population of gay/bisexual men, and because risk factor information was not available due to the blind nature of the study, it was decided to look only at results of testing done on bloods drawn from women as representative of the non gay/bisexual segment of the population.

The results showed a 0.5% seropositivity in women attending our STD clinics and a 0.5% seropositivity in women attending premarital testing sites. This means that approximately 1 in 200 women attending those clinics was infected. Again, because no risk factor information was available, it is possible that all women testing positive may have been IV drug users. One thing however, is known - that they were all sexually active or were about to be. This information has potentially grave implication for the prospects of vertical transmission and the appearance of increasing numbers of children with AIDS and ARC.

This study was done on bloods drawn between November, 1985 and May, 1986 and represents prevalence in the population almost one year ago.

When the results of this study became public in January of this year, public reaction was astounding. The number of people presenting to our anonymous test sites increased two to three fold with a dramatic shift from 10% heterosexuals before release of study results to 65-75% heterosexuals after. The general population had heard the message and understood that AIDS was no longer a disease of "Those other people". They not only realized that they might be at risk, but even more importantly, they were motivated to take some action.

This public reaction states loudly and clearly that blind seroprevalence studies are vitally necessary, not only to increase our understanding of how this disease is spreading within the population at large, but also as an educational tool and motivating force for behaviour change.

D. Prevention

The message is simple:

AIDS IS A PREVENTABLE DISEASE

This has not been said loud enough, clearly enough, simply enough or often enough. While it is not yet vaccine preventable, it is, nonetheless preventable.

Primary prevention of infection is the objective; primary prevention of infection in the individual, and primary prevention of vertical transmission to the fetus.

Toward this end, it is imperative that AIDS be made a women's health issue. This is not to imply an abrogation of responsibility on the part of men, but rather to further empower women to take responsibility for their own health and the health of their future offspring. This is to reiterate a woman's right to say no - to insist on condom use in order to avoid infection. We have seen very clearly how well this worked with contraception. Similarly, women must assert their rights to health by giving their partners a choice - either use a condom or go elsewhere!

Screening for Antibody is another means to prevent pediatric AIDS. This should be voluntary and linked to perinatal services. All women presenting at family planning, pregnancy testing and prenatal clinics should be educated regarding the transmission of AIDS. Histories should be taken to elicit any high risk exposures, and voluntary confidential testing be offered.

Attempts to mandate premarital testing should be discouraged as experience with premarital syphilis testing has proven it to be exceptionally expensive, not productive in identifying positives, and too late in that most prospective marriage partners have already been sexually active (both with others as well as with their prospective mates) well before applying for marriage licenses.

E. Treatment

Because the nature of AIDS/ARC is so very different in children, it will become necessary to establish regional pediatric treatment centers capable of providing acute and long term care as well as coordinating social and other supports surrounding outpatient services, education, financing, legal disability, and hospice services.

Within the Bay Area, there exist four facilities which could serve these purposes; UCSF, Stanford, Children's Hospital of San Francisco and Children's Hospital of the East Bay. These hospitals now serve most of Northern California as their catchement area.

F. Cost/Financing issues must be dealt with in terms of making AIDS and ARC Medicaid/Medicare eligible. Similarly, development of a national Catastrophic Insurance Plan which would cover all aspects of HIV infection and related disease must be considered.

It is clear that local jurisdictions cannot bear the cost that this disease will bring. Governor Deukmejian's recent decision to reduce Medi-Cal payments by 10% will have immediate impact on MCH and family planning outpatient interventions as well as on the more obvious inpatient costs. This decision is tantamount to asking the counties, whose revenue base was severely compromised by Prop. 13, to underwrite and subsidize the State. The counties can no more do this than can the State afford to bail out the Federal Government on what is clearly a national if not global disaster in the making. Major adjustments in the Federal Budget must be comtemplated in order to meet this growing crisis.

G. Appendices

A - CDC Weekly Surveillance Report
B - Alameda County AIDS Summary Status Report
C - Alameda County AIDS Response Plan

Appendix C:

[Alameda County AIDS Response Plan 1987, Alameda County Health Care Services Agency, Oakland, CA, is retained in committee files.]

C. AIDS CASES BY STATE OF RESIDENCE AND DATE OF REPORT TO CDC

STATE OF RESIDENCE	Year Ending DEC 29, 1985 Number	Year Ending DEC 29, 1985 Percent	Year Ending DEC 29, 1986 Number	Year Ending DEC 29, 1986 Percent	CUMULATIVE TOTAL SINCE JUNE 1981 Adult/Adolescent Number	Adult/Adolescent Percent	Children Number	Children Percent	Total Number	Total Percent
New York	2507	(30.5)	3740	(28.3)	9032	(31.6)	150	(36.6)	9182	(31.7)
California	1912	(23.2)	2778	(21.1)	6369	(22.3)	23	(5.6)	6392	(22.0)
Florida	527	(6.4)	853	(6.5)	1859	(6.5)	54	(13.2)	1913	(6.6)
Texas	482	(5.9)	955	(7.2)	1780	(6.2)	11	(2.7)	1791	(6.2)
New Jersey	469	(5.7)	776	(5.9)	1664	(5.8)	60	(14.6)	1724	(5.9)
Illinois	192	(2.3)	365	(2.8)	710	(2.5)	5	(1.2)	715	(2.5)
Pennsylvania	198	(2.4)	306	(2.3)	641	(2.2)	8	(2.0)	649	(2.2)
Massachusetts	166	(2.0)	278	(2.1)	566	(2.0)	11	(2.7)	577	(2.0)
Georgia	183	(2.2)	302	(2.3)	569	(2.0)	7	(1.7)	576	(2.0)
District of Columbia	164	(2.0)	246	(1.9)	512	(1.8)	8	(2.0)	520	(1.8)
Maryland	148	(1.8)	184	(1.4)	410	(1.4)	6	(1.5)	416	(1.4)
Washington	116	(1.4)	174	(1.3)	358	(1.3)			358	(1.2)
Louisiana	101	(1.2)	161	(1.2)	331	(1.2)	4	(1.0)	335	(1.2)
Virginia	108	(1.3)	158	(1.2)	328	(1.1)	6	(1.5)	334	(1.2)
Connecticut	88	(1.1)	157	(1.2)	318	(1.1)	12	(2.9)	330	(1.1)
Puerto Rico	95	(1.2)	130	(1.0)	295	(1.0)	18	(4.4)	313	(1.1)
Colorado	63	(0.8)	167	(1.3)	292	(1.0)	2	(0.5)	294	(1.0)
Ohio	49	(0.5)	189	(1.4)	279	(1.0)	1	(0.2)	280	(1.0)
Michigan	51	(0.7)	141	(1.1)	243	(0.8)	3	(0.7)	246	(0.8)
North Carolina	67	(0.8)	81	(0.6)	171	(0.6)	1	(0.2)	172	(0.6)
Arizona	51	(0.6)	81	(0.6)	161	(0.6)			161	(0.6)
Missouri	51	(0.6)	74	(0.6)	157	(0.5)	1	(0.2)	158	(0.5)
Minnesota	40	(0.5)	98	(0.7)	156	(0.5)			156	(0.5)
Indiana	25	(0.3)	67	(0.5)	121	(0.4)	1	(0.2)	122	(0.4)
Oregon	33	(0.4)	63	(0.5)	115	(0.4)			115	(0.4)
South Carolina	37	(0.4)	50	(0.4)	101	(0.4)	4	(1.0)	105	(0.4)
Hawaii	27	(0.3)	55	(0.4)	101	(0.4)	1	(0.2)	102	(0.4)
Tennessee	19	(0.2)	74	(0.6)	100	(0.3)	1	(0.2)	101	(0.3)
Wisconsin	24	(0.3)	42	(0.3)	78	(0.3)			78	(0.3)
Oklahoma	20	(0.2)	42	(0.3)	75	(0.3)	1	(0.2)	76	(0.3)
Alabama	29	(0.4)	31	(0.2)	69	(0.2)	2	(0.5)	71	(0.2)
Nevada	16	(0.2)	37	(0.3)	64	(0.2)			64	(0.2)
Kentucky	17	(0.2)	31	(0.2)	62	(0.2)			62	(0.2)
Kansas	12	(0.1)	37	(0.3)	53	(0.2)	1	(0.2)	54	(0.2)
Rhode Island	10	(0.1)	34	(0.3)	51	(0.2)			51	(0.2)
Utah	19	(0.2)	22	(0.2)	48	(0.2)	3	(0.7)	51	(0.2)
New Mexico	14	(0.2)	25	(0.2)	43	(0.2)			43	(0.1)
Arkansas	10	(0.1)	29	(0.2)	40	(0.1)			40	(0.1)
Delaware	11	(0.1)	23	(0.2)	40	(0.1)			40	(0.1)
Mississippi	8	(0.1)	28	(0.2)	40	(0.1)			40	(0.1)
Iowa	12	(0.1)	20	(0.2)	35	(0.1)	1	(0.2)	36	(0.1)
Maine	11	(0.1)	21	(0.2)	31	(0.1)	1	(0.2)	32	(0.1)
New Hampshire	4	(0.0)	14	(0.1)	21	(0.1)	2	(0.5)	23	(0.1)
Alaska	5	(0.1)	14	(0.1)	22	(0.1)			22	(0.1)
Nebraska	7	(0.1)	11	(0.1)	21	(0.1)			21	(0.1)
West Virginia	6	(0.1)	8	(0.1)	19	(0.1)	1	(0.2)	20	(0.1)
Vermont	2	(0.0)	5	(0.0)	9	(0.0)			9	(0.0)
Virgin Islands	1	(0.0)	4	(0.0)	7	(0.0)			7	(0.0)
Idaho	3	(0.0)	3	(0.0)	6	(0.0)			6	(0.0)
Montana	1	(0.0)	5	(0.0)	6	(0.0)			6	(0.0)
Wyoming			4	(0.0)	5	(0.0)			5	(0.0)
North Dakota	1	(0.0)	3	(0.0)	4	(0.0)			4	(0.0)
South Dakota	1	(0.0)	2	(0.0)	3	(0.0)			3	(0.0)
Guam	1	(0.0)			1	(0.0)			1	(0.0)
Trust Territory					1	(0.0)			1	(0.0)
TOTAL	8224	(100.0)	13197	(100.0)	28593	(100.0)	410	(100.0)	29003	(100.0)

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APPENDIX B

Alameda County Health Care Services Agency
Bureau of Communicable Diseases, AIDS Services
Summary Status Report of all AIDS Cases,
Cumulative with Alameda County Residency at Diagnosis

Date: 12/31/86

Persons Diagnosed to Date: 328

Date of Onset		
Pre 1983	16	5%
1983	31	10%
1984	43	13%
1985	89	27%
1986	149	45%

Ethnic Origin*		
White, non Hispanic	203	68%
Black, non Hispanic	59	20%
Hispanic	26	8%
Asian	11	4%

Age at Diagnosis		
Under 20	2	1%
20 - 29	57	19%
30 - 39	115	38%
40 - 49	75	25%
50 - 59	43	14%
60 - 69	5	2%
70 - 79	2	1%
Over 79	0	0

Sex*		
Male	291	97%
Female	8	3%

Residency*		
Oakland	163	55%
Berkeley	29	10%
Alameda	26	9%
Emeryville	4	1%
Albany	3	1%
Piedmont	3	1%
TOTAL, NORTH	228	76%
Hayward	22	7%
San Leandro	22	7%
Castro Valley	8	3%
Fremont	9	3%
Livermore	3	1%
Union City	3	1%
Newark	3	1%
Pleasanton	1	0%
TOTAL, SOUTH	71	24%

Provider at Diagnosis		
County Facil.	66	20%
Kaiser (Alameda)	76	23%
Other (Alameda)	82	25%
Total, Alameda	224	68%
San Francisco Facilities	87	26%
Not Alameda nor San Francisco	17	6%

Risk Factor*		
Gay/Bi Men, no IV use	240	81%
IV drugs, not Gay/Bi	5	2%
Gay/Bi with IV use	19	6%
Transfusion	11	4%
Hemophilia	1	0%
Heterosexual partners	3	1%
No known risk	10	3%
Other/Unknown	10	3%

Overall Mortality by Date of Diagnosis*

	Alive/Unknown		Dead		TOTALS	
Pre 1983	3	25%	9	75%	12	100%
1983	4	16%	21	84%	25	100%
1984	8	17%	39	83%	47	100%
1985	23	26%	66	74%	89	100%
1986	77	61%	49	39%	126	100%
TOTALS	115	38%	184	62%	299	100%

*Complete demographic information available for 299 cases only. San Francisco will provide this office with information for the remaining 29 cases in late January. This will be incorporated into the next report.

Chairman MILLER. Okay. Your fan club is here.

Mr. Williams?

STATEMENT OF JOHN WILLIAMS, EXECUTIVE DIRECTOR, CHILDREN'S HOSPITAL AT STANFORD, PALO ALTO, CA

Mr. WILLIAMS. Thank you. Good morning.

My name is John Williams. I am the Executive Director of Children's Hospital at Stanford, an affiliated hospital of the Stanford University School of Medicine.

Joining me in this statement is Dr. Bertil Glader, who is Associate Professor of Pediatrics at Stanford, and Director of the Hematology-Oncology Program and the Hemophilia Center at Children's Hospital. Unfortunately, with the change in date of the hearing, Dr. Glader is unable to be with us this morning.

I want to talk about AIDS, particularly for children with hemophilia. AIDS has been described as a problem of adults, either homosexual men or intravenous drug abusers. While the majority of cases have occurred in these populations, other groups are also affected.

We submit that children are also at great risk of this infection and need maximum efforts to avert the tragedy of AIDS for them and their families. Babies with AIDS soon will be a major problem as a consequence of parents who are infected because of drug abuse or sexual activities.

In addition, children who have received transfusions, particularly those with hemophilia, are at great risk for the disease. The source of the problem is that hemophilia is a congenital disorder caused by the absence of certain clotting factors in plasma, which facilitate blood clotting.

Prior to the discovery of the cause of hemophilia in the 1950s, children with hemophilia led disabled lives. They were constantly in fear of bleeding episodes, which could be fatal. Bleeding into the joints produced an arthritis-like condition which made walking difficult and sports impossible. Many children died from bleeding into the central nervous system.

With the discovery of the missing clotting factor in blood plasma, hemophiliac bleeding became amenable to control. Initially, treatment was with the infusion of plasma. During the past fifteen years, the pharmaceutical industry has developed techniques for super-concentrations and refinement of the clotting factor, and distribution in a form so that it can be administered at home. This has freed the hemophiliac to grow up much more normally, to enjoy sports and recreation, and to look forward to a greatly increased life span and to not suffer major bleeding problems.

The AIDS problem comes from the concentrates. These concentrates of factors are produced from pools of blood plasma which are obtained from as many as ten to fifteen thousand individuals for a batch of commercial concentrate. Many viruses were present in the pool product and until recently the main problem had been the transmission of hepatitis.

Since 1981, it is apparent that the concentrates are also contained the AIDS virus. Since 1985, a method of heat treating the concentrates has been discovered which renders the AIDS virus inactive. In addition, testing of the blood supply has reduced to a very low level the likelihood that plasma containing the AIDS virus, will be included in the commercial concentrates.

The problem now is hemophiliacs who used these products prior to 1986 and thus have been exposed to the virus. It is a reasonable estimate that there are 20,000 patients with hemophilia currently in the United States. As of February 1 last year, 288 hemophiliacs had been diagnosed as having clinical AIDS. This represents over one percent of all the patients with hemophilia in the country.

Antibody studies have indicated that seventy to ninety percent of all hemophiliacs have been exposed. Moreover, current studies indicate that the presence of the AIDS antibody indicates that these patients also may carry the virus and are thereby infectious.

At Children's Hospital at Stanford, we have a 130 boys and young men who are hemophiliac patients. Six of our patients, two young children and four young adults, have developed clinical AIDS; five of these have died. The other patients whom we care for, most of whom are infected, live daily with the fear that they will also develop the disease.

There are major social and educational problems for the child with AIDS and his family. First of all, the hospital staff has to be educated on how to care for these children and to protect themselves from infection. Now, once done, the care in the hospital has been smooth.

The news media have reported school boards barring children from school, even though we know AIDS is not transmitted through such casual contact. Home health care workers have been reluctant to care for AIDS children until we have been able to educate them about the disease. Siblings have been isolated from social contacts by others who fear the disease.

Another problem arises for the hemophiliac young adults who are having families. Ten to fifteen percent of the spouses of hemophiliacs are antibody positive and likely carry the virus. Babies born to antibody positive mothers, as has been said before, carry at least a fifty percent risk of also developing AIDS.

Hemophilia is a very expensive health problem. The annual costs for the clotting factor concentrates vary from as little as a $1,000 a year for a mild case to about $75,000 a year for severe cases. Other medical care, especially surgery, is complicated by hemophilia. It requires special expertise. Dental and orthopedic care is complicated and frequently costly.

AIDS is an additional financial catastrophe for children who already have a catastrophic health condition, that is hemophilia. For example, the costs of one of our children was $244,000 for the last year of that child's life.

Fortunately, California provides supplementary funding for children with hemophilia through the California Children's Services Program. This jointly-funded federal, state and county program covers children through age twenty-one. A state-funded program, the Genetically Handicap Persons Program, covers hemophiliacs after age twenty-one.

These programs have required deficiency appropriations annually in recent years. We are concerned that the cost of AIDS treatment has not been adequately reflected in the budget for these programs, and we could see the situation of children with heart problems or cancer having to compete with hemophiliacs and AIDS victims for financial support.

In addition, there are proposals to block grant the CCS program to the states and ultimately to the counties. This would put hemophiliac children at the whim of county priorities. It would put providers in the unmanageable position of different county rules for eligibility and for treatment authorization for these catastrophic conditions.

For example, at Children's Hospital at Stanford, we treated patients from forty-three California counties last year. The administrative costs and the financial risks for each county as well as for the providers of this proposed change are major problems.

Our recommendations are four.

No. 1. Assure adequate funding for AIDS research. We presently have no cure for AIDS. One must be found if we are to offer any hope to the thousands of hemophilia victims who are exposed to the virus. To combat this infection through research should be a top national priority for the sake of all of our population.

No. 2. Is expand public awareness and preventive educational campaigns. The ignorance of this disease and how it can and cannot be spread is a major problem. Children with AIDS and their families experience major problems with school, housing, and other social effects resulting from fear of the disease. We must educate ourselves about the nature of this infection and humane ways to treat its victims.

No. 3. Assure adequate funding for treatment. Hemophilia is a very expensive condition due to the cost of the blood clotting concentrates which make life possible. The cost of treating AIDS on top of these costs is a major threat to the funding of federal and state child health programs.

In addition, private health insurance sometimes excludes both hemophilia and AIDS as covered conditions. Funding for AIDS treatment must be supplementary to the underlying health care needs which both government and private programs presently fund.

We recommend establishing a national agency to focus attention on the AIDS situation and to coordinate federal activities in this area.

Thank you for the opportunity to present our views. We would be happy to respond to any questions.

[Prepared statement of John Williams follows:]

Prepared Statement of John Williams, Executive Director of Children's Hospital at Stanford, Palo Alto, CA

THE PROBLEM OF ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) FOR CHILDREN WITH HEMOPHILIA

My name is John Williams. I am the Executive Director of Children's Hospital at Stanford, an affiliated hospital of the Stanford University School of Medicine. Joining me in this statement is Bertil E. Glader, Ph.D., M.D., Associate Professor of Pediatrics at Stanford University School of Medicine and Director, Hematology-Oncology Program, and the Hemophiliac Center at Children's Hospital.

I. Introduction: AIDS has been described as a problem of adults who are homosexual men and intravenous drug abusers. While the majority of cases have appeared in these populations, other groups are also affected by this disease. We submit that children are also at great risk of this infection and need maximum efforts to avert the tragedy of AIDS for them and their families. Children with AIDS soon will be a major problem as a consequence of parents who are infected because of drug abuse or sexual activities. In addition, children who receive transfusions, particularly those with hemophilia are at great risk for this disease.

II. Source of the problem: Hemophilia is a congenital disorder caused by the absence of certain clotting factors in plasma which facilitate blood clotting. Prior to the discovery of the cause of hemophilia in the 1950's, children with hemophilia led disabled lives, constantly in fear of a bleeding episodes which could be fatal. Bleeding into the joints produced an arthritis-like condition which made walking difficult and sports impossible. Many children died from bleeding into the central nervous system.

With the discovery of the missing clotting factor in blood plasma, hemophiliac bleeding became amenable to control. Initially, treatment was with infusion of plasma. During the past 15 years, the pharmaceutical industry has developed techniques for super concentration and refinement of the clotting factor and distribution in a form so that it can be administered at home. This has freed the hemophiliac to grow up much more normally, to enjoy sports and recreation, and look forward to a greatly increased life span and not to suffer major bleeding problems.

III. The AIDS problem: These concentrates of clotting factors are produced from pools of blood plasma obtained from as many as 10,000-15,000 individuals for a batch of commercial concentrate. Many viruses were present in the pooled product and, until recently, the main problem had been the transmission of hepatitis. Since 1981 however, it is apparent that these concentrates also contained the AIDS virus.

Fortunately, since 1985, a method of heat treating the concentrates has been discovered, which renders the AIDS virus inactive. In addition, testing of the blood supply has reduced to a very low level the likelihood that plasma containing the AIDS virus will be included in commercial plasma concentrates. The problem now is hemophiliacs who used these products prior to 1986 and thus have been exposed to the virus.

IV. Extent of the problem: It is a reasonable estimate that there are 20,000 patients with hemophilia currently in the United States. As of February 1, 1986, 288 hemophiliacs have been diagnosed as having AIDS. This represents over one percent of all patients with hemophilia in this country. Antibody studies have indicated that 70%-90% of all hemophiliacs have been exposed. Moreover, current studies indicate that the presence of the AIDS antibody indicates that these patients also may carry the virus and thereby are infectious.

At Children's Hospital at Stanford, we have 130 boys and young men who are hemophiliac patients. Six of our patients (two young children and four young adults) have developed clinical AIDS. Five of these have died. The other patients who we care for, most of whom are infected, live daily with the fear that they also will develop the disease.

There are major social and educational problems for the child with AIDS, and his family. First of all, the hospital staff has to be educated on how to care for these children and to protect themselves from infection. Once done, care in the hospital has been smooth. The news media has reported school boards barring these children from school, even though we know AIDS is not transmitted through such casual contact. Home health care workers have been reluctant to care for AIDS children until we have been able to educate them about the disease. Siblings have been isolated from social contact by others who fear the disease.

Another problem arises for the hemophiliac young adults who are having families. 10%-15% of the spouses of hemophiliacs are antibody positive and most likely carry the virus. Babies born to antibody positive mothers carry at least a 50% risk of also developing AIDS.

V. Costs of care: Hemophilia is a very expensive health problem. The annual costs for the clotting factor concentrates varies from as little as $1,000 for a mild case to $75,000 for severe problems. Other medical care, especially surgery, is complicated by hemophilia. It requires special expertise. Dental and orthopedic care is complicated and frequently costly. AIDS is an additional financial catastrophe for children who already have the catastrophic health condition of hemophilia. For example, the costs for one of our children was $244,000 for the last year before he died.

Fortunately, California provides supplementary financing for children with hemophilia through the California Children's Services (CSC) program. this jointly funded (federal, state and county) program covers children to age 21. A state-funded program, the Genetically Handicapped Persons Program (GHPP) covers hemophiliacs after age 21.

These programs have required deficiency appropriations annually in recent years. We are concerned that the costs of AIDS treatment has not been adequately reflected in the budgets for these programs. Children with heart problems or cancer may have to compete with hemophilia and AIDS for financial support.

In addition, there are proposals to block grant the CCS program to the states and ultimately the counties. This would put hemophiliac children at the whim of county priorities. It would put providers in the unmanageable position of different county rules for eligibility and treatment authorization for these catastrophic conditions. For example, Children's Hospital at Stanford treated patients from 43 California counties last year. The administrative costs and the financial risks to each county of this proposed change are major problems.

IV. Recommendations: A. Assure adequate funding for AIDS research. We presently have no cure for AIDS. One must be found if we are to offer any hope to the thousands of hemophilia victims who have been exposed to the virus. To combat this infection through research should be a top national priority for the sake of all our population.

B. Expand public awareness and preventive educational campaigns. The ignorance of this disease and how it can and cannot be spread is a major problem. Children with AIDS and their families experience major problems with school, housing and other social effects resulting from fear of the disease. We must educate ourselves about the nature of this infection and humane ways to treat its victims.

C. Assure adequate funding for treatment: hemophilia is a very expensive condition due to the cost of the blood clotting concentrates which make life possible for these individuals. The costs of treating AIDS on top of these costs is a major threat to the funding of federal and state child health programs. In addition, private health insurance sometime excludes both hemophilia and AIDS as covered conditions. Funding for AIDS treatment must be provided supplementary to the underlying health care needs which both government and private programs presently fund.

D. Establish a national agency to focus attention upon the AIDS situation and to coordinate federal activities in this area.

Chairman Miller. Thank you.

Ms. McIntosh?

STATEMENT OF JEAN McINTOSH, M.S.W., ASSISTANT DIRECTOR, LOS ANGELES COUNTY DEPARTMENT OF CHILDREN'S SERVICES, LOS ANGELES, CA

Ms. McIntosh. Good morning.

I am Jean McIntosh, the Assistant Director from the Department of Children's Services in Los Angeles County.

Chairman Miller. We need you to move the mikes over.

Ms. McIntosh. All right.

We represent approximately forty percent of the children in the child welfare system in California. At any one point in time, we serve approximately 43,000 children. Approximately 29,000 of those children are under the dependency system of the Juvenile Court, and of those, about 20 percent—I am sorry. 20,000 children are in foster placement.

My perspective is that of the child welfare professional——

Chairman Miller. You need to lean into the mike. I can see that the audience cannot hear you.

Ms. McIntosh. Okay. My perspective is that of the child welfare professional, and some of the critical policy issues that we see relate to the health services profession, but I think it is a slightly different perspective for the members here to consider.

As you know, we have seen drastically increasing numbers of child abuse and neglect cases coming to child welfare agencies. This is due, I think, to Public Law 96-272 passage, to increased reporting responsibilities and to wonderful public education that has taken place, that has helped children who are vulnerable to come to our attention.

Two major groups that we have seen increasing here are those children who are either addicted at birth to drugs, who are exposed perinatally to drugs, or whose parents are so involved with substance abuse that they cannot care for these children.

I want to give you some statistics because I think they are very revealing. These are from Los Angeles County. Between 1981 and 1986, we saw an 1100 percent increase in the number of children coming before the Juvenile Court because their parents could not care for them because they were involved with drug abuse.

On top of that, in addition, between 1981 and 1986, we saw a 933 percent increase in children who were born addicted to drugs or who had ingested drugs soon after birth.

Of the total number of petitions filed before our Juvenile Court in that same time frame, 1981 to 1986, we saw in 1981 only four percent of the petitions filed related to these two instances; that is, parents abusing drugs or children addicted. In 1986, twenty-one percent of the total 20,000 petitions filed before Juvenile Court represented minors in these areas.

It was interesting as we were looking at statistics to pull together for this hearing, these ranges of figures for the period 1981 to 1985 were somewhere in the 400 to 600 percent increase range. When we added in the single year of 1986, those percentages jumped to between 900 and 1100 percent.

What that says to us is that we have a geometric increase in the number of children at risk to AIDS because of the clear connection between drug addicted and IV mothers and their children.

I think if we look at these children and how we protect them, we then need to look at the foster care system. We know in the last four or five years that we have seen increasing difficulty recruiting foster parents to care for infants and toddlers. I think when you add to that the fact that we are seeing increasing numbers of medically-fragile children, including these drug addicted babies, and then when you add to that the evidence that we are now hearing that there are going to be increasing numbers of children who contract AIDS as a result of their parents' IV drug use, you can see that we are going to have fewer and fewer foster parents who are going to be able and willing, capable of caring for these young children.

That says several things. First of all, it says that we may have less likelihood of having these children in a family setting in a community. That means then that they will need to be placed in either government shelter care facilities or in congregate care facilities.

I think of interest to you may be our own shelter in Los Angeles. In November of 1981—I am sorry, 1982, the approximate number of infants and toddlers in our nursery was nine, and when we reached the population of fifteen, all the panic bells went off. In November of 1986, the average population of our nursery at MacLaren Children's Center was ninety, and we are currently now running between sixty and eighty children, infants and toddlers, in our shelter because we do not have placements in the community, either group homes or foster care, for these children.

I think another issue that we have to consider in the dependency system is the issue of permanency planning because it was one of the critical thrusts of child welfare legislation.

My concern is that with the increased numbers of children coming into the protective system at a very young age, with linkage to substance abuse and then with our growing information about the linkage between substance abuse and AIDS, that for permanency planning purposes, we are going to see these children more likely to be freed because their parents' debilitating drug use will not enable them to provide homes, but we are going to see them not having been raised in families, foster families, as often and, therefore, less able to establish familial-type relationships and we will see, I think, fewer and fewer adoptive parents willing to take the risk of bringing one of these youngsters into their home on a permanent basis.

As we have heard, medically, these children can be time bombs, if you will. They may present medical problems over a course of years. They may have physical, developmental, neurological problems, and we are finding even today that adoptive parents who come to us are saying, if the child has had involvement with drugs, if the child's parents were addicts, we are not going to be able to consider the child, even a baby, even a baby, to come into our home.

I think there are a couple of other issues that are equally as startling. We have seen an increase in the number of youngsters who are sexually abused coming into the system. Between 1981 and 1986, in our county, there was a 178 percent increase in the number of these children coming before the Juvenile Court. That represented some 4,000 cases.

We know of the linkage between sexual contacts and AIDS. I think that what we are going to be seeing is that these children come to us as sexual abuse victims may be victims on two counts; one, having been the victims of child sexual abuse, and, two, having a higher risk of contracting AIDS because of that.

Thirdly, I think that there is an issue with teen pregnancy and AIDS. Adolescence is a time when youngsters begin sexual experimentation. Our children in the child welfare system are separated from their families. Many of them have behavioral problems, and I think what we may see is that these children, both in their sexual experimentation as well as in the fact that they are of child-bearing age, are at risk to contracting AIDS themselves as well as to bearing children who may be at high risk.

I think that we in the child welfare system also have a responsibility for how we educate these children. Dr. Grossman raised a very important point. A lot of the children that we serve in child welfare are not in school regularly and they are not going to benefit from those traditional programs.

We need to think about what is the responsibility of the dependency system to educate these special needs children. I think we need to think very creatively about the blending of funding streams. The issue of cost, Mr. Stark, is incredible, and I think that we need to take a look at the fact that these children, by virtue of not perhaps looking at foster care regulations in terms of reimbursement for training, for special support services, I think that we can keep more of these children in lower levels of care if we had support services available, and if there was a blending of funding streams to allow health care issues to be met.

I have submitted additional information for consideration, which regards some specifics that L.A. County is interested in.

I thank you very much for the opportunity to allow all of us to engage in this discussion. It is very important. I think, for those of us who may want to think that the window of opportunity is ahead of us, we are being shortsighted. We need to look at this window of opportunity now. We are out of time.

Thank you very much.

[Prepared statement of Jean McIntosh follows:]

PREPARED STATEMENT OF JEAN MCINTOSH, M.S.W., COUNTY OF LOS ANGELES, DEPARTMENT OF CHILDREN'S SERVICES

Good Morning Representative Miller and distinguished Committee Members.

I am Jean McIntosh, Assistant Director of the Los Angeles County Department of Children's Services. Our Department is responsible for carrying out the Title IV-B Child Welfare Services and Title IV-E Foster Care Maintenance Payments and Adoption Assistance Programs initiated by P.L. 96-272, the Adoptions Assistance and Child Welfare Act of 1980. The Department serves 43,000 abused and neglected children at any point in time; 29,000 of these youngsters are dependents of the Juvenile Court (20,000 of these are in foster care).

We applaud the Committee's concern about this very important issue and thank you for including us in this discussion.

My statements today will focus on how the dependent care system will be stressed by children with AIDS:

- The increased severity of abused and neglected children coming into the Child Welfare System - the impact of drug abuse and sexual molestation;

- Activities at the local level to begin to address issues of young children with AIDS;

- The resource implications and specialized care needed in both the Child Welfare and Foster Care programs.

CHILDREN AT RISK: GREATER NUMBERS, MORE HARM

The past five years have seen a major increase in the allegations of child abuse and neglect. This reflects mandated child abuse reporting statutes and community awareness and attention. In conjunction with the growth in reported incidences, the severity of cases has also increased. The child welfare/foster care system has seen a dramatic increase in the numbers of high risk children needing child protective services. Incidences of substance abuse and sexual molestation are of particular concern.

CHILD WELFARE/DRUG ABUSE INTERACTION

Of primary importance to child welfare advocates is the correlation between AIDS, drug abuse, and sexual molestation. Comparable to other human service agencies, child welfare has seen the unfortunate increase in drug-related incidents which endanger children. Our Juvenile Court intake statistics on dependency petition filings demonstrate this pattern. A petition is a legal document submitted to the Juvenile Court by the children's services worker containing allegations to show why a minor should be declared a dependent child of the Juvenile Court. The goal of initiating Juvenile Court actions is to protect the child. Our 1981-1986 data on petition requests demonstrate the alarming increase in allegations of substance abuse: this includes drug withdrawal/ingestion by young children as well as debilitating drug use by a child's parents.

* Excessive drug use by a parent:
  1981 - 241 cases
  1986 - 2,857 cases; a 1100% increase
* Drug ingestion of minor or infant in drug withdrawal:
  1981 - 132 cases
  1986 - 1,363 cases; a 933% increase

In 1981, substance abuse related referrals represented 4.09% of the total 9,133 petitions filed.

In 1986, substance abuse related referrals represented 21% of the total 20,096 petition filed.

Of particular concern is the increase in these petitions between 1985 and 1986. Parental drug abuse increased by 60%. Drug ingestion by a minor increased by 69% in the same one year period. This demonstrates that substance abuse is expanding not only on a cumulative basis, but also on a geometric basis!

Our Board of Supervisors has recognized the growing problem of substance abused infants and has instructed our Chief Administrative Office to coordinate the efforts of County Departments to develop recommendations and activities to address this problem. This includes a media campaign, development of protocols on maternal substance use and neonatal drug withdrawal and coordination of efforts among our local law enforcement agencies and the Departments of Health Services and Children's Services.

Problem

Pregnant women who use drugs present an enormous national problem. Hospitals, Departments of Social Services and law enforcement are seeing an increasing number of infants who are born under the influence or addicted to drugs. Drugs involved include PCP, heroin, cocaine and other illegal drugs. Often, mothers use more than one drug. Newborns whose parents are prostitutes and/or intravenous drug abusers are at a high risk of being seropositive and contracting AIDS.

Effects of Drug Use

There are many harmful effects of prenatal drug exposure.

These infants have special needs that require special care.

- Infants born to substance abusing women characteristically are premature, poorly nourished and neurologically abnormal as a result of their drug exposure.

- Mental retardation and seizure disorders are now well-recognized complications of fetal drug and alcohol exposure.

- Other problems include sleeping and feeding disorders, vomiting, diarrhea, tremors, high-pitched crying and excessive movements; increased risk of Sudden Infant Death Syndrome (SIDS).

The follow-up studies of these children have shown poor growth and developmental delays. When they enter school, they are almost sure to have learning problems.

Investigation and Protection

The Department of Children's Services (DCS) is working with county-wide law enforcement agencies to develop procedures that will trigger an immediate investigation of children living at the home of an arrested drug suspect.

We have an Emergency Response Command Post to respond to referrals 24 hours a day, seven days a week. It is designed to provide an immediate investigation by a CSW after normal department working hours. CSWs are housed at six law enforcement stations throughout Los Angeles County.

We support, and work with law enforcement toward, the goal of referring drug cases where there is a suspicion that drug activity has endangered children residing in the home. We have also emphasized with law enforcement that whenever their officers have questions concerning the safety of a child in a drug case, they should refer the case to DCS for evaluation, even if the children are not taken into temporary custody.

Permanency Planning

Infants are generally placed with relatives or foster parents until parents are able to provide safe care. Mother/child residential treatment centers are few and needed.

Parents' participation in a drug treatment program is considered essential. Feedback from treatment programs is essential for monitoring progress. Drug use must be controlled before other parenting issues are addressed. Frequent and unannounced home calls are made.

Because of their tender age and consequent high risk, infants and toddlers needing protection due to drug abuse situations are often placed in foster care. Nationally, recruitment of foster families for pre-school children is becoming more and more difficult due to social and financial considerations. Compounding this trend is the fact that those foster parents we do recruit are often afraid to care for such medically fragile children. Now, we are facing the alarming possibility that a significant proportion of these children are at risk to AIDS. It is not hard to imagine that potential foster parents may move away from caring for these vulnerable children to protect their own families!

We are already beginning to see greater numbers of high risk infants and toddlers going into government-run shelters and private sector congregate care facilities. For example, the Los Angeles County shelter for abused and neglected children had an average daily population of nine children under the age of five (5) in November 1982.

In November, 1986, the average number of children in our shelter's nursery was 90!

Equally disturbing is the fact that young children are increasingly being placed in group homes rather than in foster families. The number of foster family spaces for infants and toddlers has remained approximately even at 7,800 over the past six years, while the number of spaces for these little ones in group homes and institutions has increased from 70 in 1980 to 170 now – with at least 64 more spaces opening in three new facilities by April 1987.

It is clear that current trends in foster care may show young children more often placed in group homes and institutions. Given what we know about the social and physical isolation that is attendant to AIDS and even AIDS-Related Complex (ARC), young children so afflicted may have significantly reduced hope for foster placement with a nurturing family. Not only will the social costs be great; the fiscal ramifications for the foster care system are enormous.

Because of the debilitating effects drug abuse has on parents, these children may not return home and may be freed for adoption. However, potential adoptive parents are now expressing reluctance to adopt these children because of the "timebomb" medical unknowns these children potentially represent. As the tie between maternal drug use and pediatric AIDS becomes more pronounced, the chances of adoption - or even placement with relatives - may decrease significantly.

The child welfare system may then be confronted with a growing number of "legal orphans" - despite our best permanency planning efforts. Unfortunately, I am afraid we are just beginning to understand the potential magnitude of pediatric AIDS

- on children and their families
- on foster care resources
- on medical resources

SEXUAL ABUSE AND AIDS

Referrals of children who are the victims of sexual molestation have also increased since the enactment of P.L. 96-272. In 1981 there were 1,361 sexual abuse petitions filed in Juvenile Court. In 1986 there were 3,778 such cases; a 178% increase.

Given what we know of the linkage between sexual contact and AIDS, children who are victims of sexual abuse would seem to be at higher risk of contracting AIDS or ARC. Unfortunately, child welfare professionals may soon be confronted with young children who are not only traumatized by the sexual abuse they have experienced, but also by medical (even life-threatening) realities they may face later in childhood and adolescence.

TEEN PREGNANCY AND AIDS

As we know all too well, teen pregnancy is increasing nationally at a disturbing rate. Teens, then, present two potentially critical problems when we think about AIDS:

- adolescence is a time of sexual awakening and can include sexual experimentation. To the extent that AIDS is linked to numbers of sexual contacts, teens — especially those who are disturbed and alienated from their families — may be at higher risk of contracting the disease;

- pregnant teens may compound the problem by being at risk to AIDS/ARC themselves and by having a baby similarly afflicted.

Many teens in the dependency care system today may face these problems. As caretakers, what is our responsibility to educate them about the risk of AIDS? Are we in child welfare going to have sufficient foster care and medical resources to meet the needs?

LOS ANGELES COUNTY, CHILD WELFARE, AND AIDS

In response to community concerns on the implications of AIDS, our Department has developed protocols and policies to anticipate AIDS cases, as there is no AIDS crisis in the Child Welfare system – yet.

The Los Angeles County Department of Health Services AIDS Report for December 31, 1986, shows that of the 2,559 cases reported, only 15 are pediatric. The incidence of pediatric AIDS has always been, and currently remains, very low in Los Angeles County. The children at greatest risk are those who received blood or blood products transfusions prior to March 1985, and infants born to mothers who engage in risk behavior including prostitution and intravenous drug abuse. As AIDS appears to be expanding in the general population, our Department has taken a comprehensive planning approach to anticipate problems in dealing with this volatile issue.

Although the placement numbers are small, AIDS or AIDS Related Complex (ARC) impacts our Department in three ways:

* It affects some of the children we serve.
* It affects our foster care providers, and
* It affects our social work staff in their professional capacities and their personal concerns.

Protocols have been developed to provide staff with factual information about:

- how AIDS is and is not transmitted
- confidentiality requirements
- personal and environmental hygiene procedures, which may be shared with foster care providers
- AIDS testing
- uniform policy and procedures for the placement of children with AIDS, ARC and positive AIDS virus (HIV) tests, and,
- AIDS resources for counseling, education, and support groups.

Overall goals of our AIDS policy are to:

- Provide appropriate placement settings for children with AIDS or ARC;
- Assure that no children in placement, Departmental staff, or foster care providers are at risk because of co-placement or contact with a child with AIDS; and to
- Educate staff and foster care providers how to accomplish those two goals.

Children who have AIDS or ARC but who are well enough to be in a foster care setting should be placed with the smallest possible child population. This is for their own sake, to limit their exposure of the viruses and germs of other children.

We also recommend that no more than one child with AIDS or ARC be placed in any foster/group home at any given time.

- This is to protect the ill child; and
- To limit the stress on the caretaker, as caring for a child with a possibly fatal illness is physically and emotionally draining.

Children who test positive to the AIDS antibody but do not have AIDS or ARC do not require special placement procedures, but confidentiality requirements and hygiene procedures are to be followed. Our Department of Health Services staff are available to counsel and train foster care providers who are willing to care for children with AIDS and ARC.

TRAINING

- The Department is working to develop a pool of foster parents specifically trained to deal with substance abuse babies. Recruitment is targeted on health services professionals.

- We are working with the Augustus Hawkins Mental Health Center and King/Drew Medical Center to expand substance abuse training for foster parents.

- We are also working with UCLA on a Federal grant to jointly train foster parents and public health nurses to care for infants exposed prenatally to drugs.

- Our Staff Development Section has incorporated substance abuse training into our ongoing in-service training program for line children's services workers and foster parents.

FOSTER CARE PAYMENTS

- Because of the severity of the problems faced by drug addicted infants and the need for ongoing supervision, a "specialized" care increment is added to the payment rate for these infants.

- Our basic foster care monthly payment for children ages infant - four years is $294.00. We have added an additional $261.00 to bring the payment to a total of $555.00 per month.

RESOURCE IMPLICATIONS: CAN P.L. 96-272 BE FULLY IMPLEMENTED?

These difficult problems demand more sophisticated service programs, foster parenting, and specialized group care. Los Angeles County recommends creative funding approaches focused to maximize existing resources and increase development of specialized service programs to reflect the increased severity of cases.

The increased volume of calls, combined with the increased severity of referral allegations, have demonstrated a critical "gap" in our child protection system — the availability of pre-placement preventive services.

Because the primary concern of P.L. 96-272 is to protect the child while preserving the family unit whenever possible, the cornerstone of successful implementation rests with our ability to provide an appropriate array of supportive services to strengthen the family's ability to safely care for the child. We believe it is essential that we analyze the problems our system has in meeting this goal. The increased severity of cases provides an obligation to review service needs and to take a fresh look at the gaps in our system in an effort to build an effective support network for families and children at-risk. Specialized needs such as treatment for AIDS, drug-addicted infants and victims of sexual abuse need to be supported and developed. Congress needs to recognize changes in society and in the composition of the children served by P.L. 96-272.

As we explore ways to institute such programs, the Department is reaching out to the private sector and is developing an approach which recognizes that the community shares in the responsibility of protecting its children. We are forging service relationships, trying to streamline our referral system, and we are implementing pilot projects to try different intervention strategies. In order to make P.L. 96-272 work, we need additional funding for ancillary services which can help a family improve their ability to raise children in a safe environment. For us in Los Angeles County, counseling, home-based services, and respite care will make that difference.

Priority attention should be given to the availability of emergency shelter care and appropriate placement resources for adolescents, infants, substance abused infants and hard-to-place children. If children must go into foster care, foster family homes should be readily available. Group home and institutional placements — however appropriate for certain children should not be the sole placement option.

The development of appropriate placement resources for the 1980s requires coordinated action at the Federal and State levels among the social services, developmental services, mental health and health programs. The increased complexity of cases entering the child welfare system is demonstrating the multiplicity of problems that cut across categorical funding streams. The new realities of the 1980s also require the child welfare system to concentrate on improving interactions with these agencies and their local counterparts, as well as with law enforcement.

Congress should initiate review of the child welfare and foster care system to strengthen the system established by P.L. 96-272. Issues needing attention include foster parent training, recruitment, licensing support and rate-setting. Particularly important is the availability and funding for emergency shelter care and appropriate placement resources.

We are approaching a difficult and demanding future as we confront the many problems of children and AIDS. Let's not be foolish and think that the window of opportunity will open sometime in the future. The opportunity is here; for the welfare of endangered children, let's seize it.

APPENDIX

The Board of Supervisors in Los Angeles County has adopted the following legislative policy guidelines developed by the Department of Health Services in response to concerns identified in our community on AIDS.

POLICY GUIDELINE: AIDS AND AIDS-RELATED COMPLEX

Favor legislation that increases eligibility and state and federal reimbursement for health care to AIDS-related Human Immunodeficiency Virus (HIV) patients.

ISSUE STATEMENT:

AIDS is probably the greatest public health threat of the 20th Century. In Los Angeles County from November 1985 to June 1986, 634 cases have been reported averaging approximately 80 cases per month. Approximately 56% of reported cases are already dead. Hospitalization costs for AIDS patients are now covered under the Medi-Cal (Medicaid) Program. There are many individuals, however, who are being admitted to county hospitals, who do not fall under the definition of AIDS. They suffer from AIDS-Related Complex (ARC) and are not covered by the Medi-Cal Program. ARC is a term with various interpretations but it usually means antibody positivity with specific clinical symptoms or illnesses short of the Federal Centers for Disease Control (CDC) definition of AIDS.

There is a need at both the state and federal levels to base eligibility for funding on the totality of the AIDS-related infection which is presently being referred to as Human Immunodeficiency Virus or HIV. Eligibility for services for HIV patients would allow counties to be reimbursed under Medi-Cal and Medicare not only for individuals with AIDS as defined by the CDC, but also for services to individuals from the point of HIV infection.

POLICY GUIDELINE: AIDS-RELATED COMPLEX - MEDICAID (MEDI-CAL) ELIGIBILITY

Provide that a diagnosis of an AIDS-Related Complex (ARC) in an individual shall create a presumption of disability for the purpose of determining eligibility for Medi-Cal.

ISSUE STATEMENT:

Existing state law provides for presumptive disability due to an AIDS diagnosis. In addition, AIDS is recognized under the federal Social Security presumptive disability criteria. However, there is no presumptive disability due to AIDS-Related Complex (ARC) under state or federal law.

The County Department of Health Services estimates that county facilities provide care for 20% to 25% of all AIDS and ARC patients receiving hospital care. The cost of treating these patients is high because of their longer than average hospital stays, need for psycho-social support services and other factors.

This legislative proposal could result in additional federal and state financial assistance to counties to help offset the costs of health care to AIDS and ARC patients.

POLICY GUIDELINE: AIDS - WAITING PERIOD FOR MEDICARE ELIGIBILITY

Favor legislation that would eliminate the 24-month waiting period for Medicare eligibility when Social Security disability is based on AIDS.

ISSUE STATEMENT:

Existing federal law requires an individual to be in receipt of Social Security disability for 24 continuous months before he/she is eligible for Medicare. AIDS is recognized under the Federal Social Security presumptive disability criteria.

Data estimates compiled by the Centers for Disease Control indicate that California has a disproportionately high percentage of AIDS patients, reported at approximately 23% of the total AIDS patients nationwide.

Existing law provides for the presumption of disability for the purpose of determining eligibility for Social Security. However, once AIDS has been diagnosed, the short survival span often precludes AIDS victims from ever obtaining Medicare coverage because they die before 24-month waiting period elapses, even though they have qualified for Social Security disability.

This legislative proposal would enable an individual diagnosed with AIDS and eligible for Social Security disability to, in addition, immediately qualify for Medicare, thereby providing faster financial assistance to offset the cost of health care.

POLICY GUIDELINE: AIDS-RELATED COMPLEX - MEDI-CAL REIMBURSEMENT RATE

SUMMARY:

Establish a pilot program to determine the appropriate level of Medicare and Medi-Cal reimbursement rates for treatment of Human Immunodeficiency Virus (HIV) patients and expand Medi-Cal coverage to provide alternative modes of post-acute care.

ISSUE STATEMENT:

Existing federal law authorizes Medicare after two years of disability for persons diagnosed with AIDS, as defined by the Centers for Disease Control. State law authorizes presumptive disability based on an AIDS diagnosis for Medi-Cal assistance. It also specifies the services qualified for assistance under the Medi-Cal program of which most are inpatient services. Reimbursement for outpatient services is very low. In addition, reimbursement for alternative modes of care such as in-home medical services and hospice care is limited. Acute hospital care costs significantly more than the alternatives of home health, skilled nursing and Hospice care.

This legislative proposal to establish a pilot project would provide a basis for determining the extent to which additional state and federal financial assistance to counties is necessary to help offset the cost of providing care to AIDS and ARC patients and would provide for a better determination of the use of alternative and less costly modes of care.

COUNTY OF LOS ANGELES
DEPARTMENT OF CHILDREN'S SERVICES

ADMINISTRATIVE DIRECTIVE

NUMBER	DATE ADVANCE

SUBJECT: PROTOCOLS FOR DCS CHILDREN WITH AIDS, AIDS-RELATED COMPLEX (ARC), AND POSITIVE HIV TESTS

REFERENCE: Memoranda from Jean McIntosh to William E. Stevens and Helen Ramirez, dated December 4, 1985 and January 7, 1986, Re: Children With AIDS

CANCELS: Above-referenced memoranda

FILE IN:
CSH 9000
AH 6-6
DH 59000

CANCEL DATE: None

I. PURPOSE

This is to provide protocols for all DCS staff who come into physical contact with children with AIDS, ARC and positive AIDS virus (HIV) antibody tests in Bureau of Protective Services cases, Bureau of Adoptions and Community Services cases, or at MacLaren Children's Center, and for those staff who have access to case records and information.

These protocols are based on the most up-to-date medical and legal information available. They are designed to: 1) reassure staff that they are not at risk within the caseworker-child relationship with a child who has AIDS, AIDS-Related Complex (ARC), or is HIV positive; 2) describe the routine hygiene measures to follow in caring for these children; and, 3) implement placement procedures which are in the best interest of these children.

This material is effective immediately.

II. OVERVIEW

This material is divided into the following major subjects:

Part III., DEFINITIONS, provides definitions of AIDS terminology.

Part IV., PERSONAL AND ENVIRONMENTAL HYGIENE, describes how AIDS is transmitted, how it is not transmitted, and the routine hygiene procedures which should be used by a person who comes into contact with the body fluids of an AIDS, ARC, or HIV positive child.

Part V., PLACEMENT PROCEDURES, describes the procedures and resources for placing a child with AIDS or ARC into a foster care setting.

Part VI., SPECIAL CONSIDERATIONS, discusses aspects which are unique to AIDS, ARC and HIV positive cases, and lists resources for dealing with AIDS-related needs.

Part VII., HIV ANTIBODY TESTING, discusses how and when individuals can obtain testing.

III. DEFINITIONS

A. HIV is the acronym for human immunodeficiency virus. This is the current name for the virus which causes AIDS. It has replaced earlier terminology, e.g., ARV (AIDS-associated retrovirus), LAV (lymphodenopathy-associated virus), and, the term most commonly used in the United States, HTLV-III (human T-cell lymphotropic virus type III).

HIV, HTLV-III, ARV, and LAV all refer to the AIDS-causing virus.

B. OPPORTUNISTIC INFECTIONS are infections which would normally either not be found, or produce only mild illness, in a person with a normal immune system. When a person's immune system is suppressed, however, opportunistic infections result in serious, often fatal illnesses.

The opportunistic infections most commonly associated with AIDS are: Pneumocystis carinii pneumonia (PCP); a type of cancer, Kaposi's sarcoma (KS); candidiasis (yeast infections); persistent cytomegolovirus (CMV); unusually extensive herpes of prolonged duration; cerebral toxoplasmosis; and, a rare form of TB.

C. ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) is a disorder in which a person's immune system is severely suppressed. It is caused by the HIV virus.

Presence of HIV alone does not constitute "full-blown" AIDS. In order for a person to be diagnosed as having AIDS, the virus, immune system suppression, and an opportunistic infection must all be present.

The symptoms of HIV infection include: unexplained weight loss; severe night sweats; swollen lymph nodes not attributed to another illness; profound, unexplained fatigue; persistent, prolonged, and unexplained diarrhea; unexplained, persistent, heavy dry cough; blurred vision and severe headaches; easy bruising; and, rashes.

D. AIDS-RELATED COMPLEX (ARC), also known (somewhat inaccurately) as "pre-AIDS" is the presence of HIV in a patient who exhibits some or all of the symptoms of HIV infection but not an opportunistic infection.

ARC does not inevitably develop into AIDS, although it may.

E. HIV POSITIVE means that a blood test has indicated the presence of antibodies to the HIV virus. This means that at some point the person has been exposed to the virus and the immune system has responded by producing antibodies.

People who have the antibody but are otherwise asymptomatic for AIDS or ARC are referred to as "HIV positive only." This condition does not inevitably begin a progression to ARC and/or AIDS, although it may. These people may be capable of transmitting the virus through risk behaviors, as described below.

IV. PERSONAL AND ENVIRONMENTAL HYGIENE

A. There are two primary methods of avoiding the AIDS virus. They are: 1) avoidance of "risk behaviors"; and, 2) routine hygiene practices.

Since HIV is transmitted most readily via the blood and/or semen of a person with the virus, "risk behaviors" are those which bring a person into intimate contact with these fluids. The most common routes of transmission are: intimate sexual contact; sharing of unsterilized hypodermic needles; blood or blood products transfusions given prior to March, 1985; and maternal transmission to an unborn or newborn child.

Although HIV is often deadly to its host, outside the body it is actually a fragile virus, easily killed by many common household products, e.g., soap, detergent, bleach, Lysol, hydrogen peroxide, and isopropyl alcohol.

HIV is not transmitted by any form of contact which is appropriate between a caseworker and a child or a foster parent and a child. It is not airborne; therefore it is not transmitted through coughing. It is not transmitted through the saliva or tears of an AIDS patient. Although the virus has been found in these fluids of some patients, the quantity is too small to pose a risk to a well person.

Several long-term studies of health care workers who care for AIDS patients and family members who live with AIDS patients have shown that close, non-sexual shared living arrangements with a person with AIDS have not transmitted the virus. This has been shown to be true even among families with questionable hygiene practices and where no special precautions were taken because it was not known that the person had AIDS. These studies show that the virus is not transmitted from toilet seats, doorknobs, dishes, eating utensils, drinking cups, or swimming pools. AIDS is not spread by talking with an AIDS patient, shaking hands, hugging, casual (as opposed to "deep") kissing, or physical proximity.

Caseworkers and foster care providers observing the simple hygiene routines listed in Part IV.B., can safely care for and be with a child with AIDS, ARC, or a HIV positive test.

It is safe to carry these children in your arms, transport them in your car, hug them, hold their hands, dry their tears, change their diapers, or give them a kiss on the cheek. Protective clothing or devices are not needed by caseworkers or foster care providers except when the wearing of disposable gloves is recommended, as described in Part IV. B.1.b. and c.

B. AIDS is a bloodborne infectious disease. Although it is known that it is very difficult to transmit by non-intimate methods, it is a disease and common-sense precautions are indicated. As with any other bloodborne infectious disease, there are recommended hygiene practices to follow.

They are equally applicable to AIDS, ARC and HIV positive cases.

1. PERSONAL HYGIENE

   a. Do not allow the child to share toothbrushes or razor blades.

   b. Avoid blood-to-blood contact. If you have a skin rash or an open cut on your hands, wear disposable gloves while cleaning up spills of blood, semen, bloody saliva, urine, feces, or vomit.

      If you do have skin contact with these substances, wash the affected areas with soap under running water for 10 seconds.

   c. Wash your hands with soap before and after changing a diaper. Gloves are not needed unless the feces are bloody, in which case, disposable gloves may be used. The AIDS virus has not been found in feces itself.

   d. If the child is drooling, wipe up the saliva with a tissue and discard the tissue. Wash your hands with soap.

   e. If the child bites you and draws blood, wash the area immediately with soap and water. As you would with any human bite wound, see a doctor.

      If this occurs in the course of your DCS duties, report the incident to your supervisor and follow the established Industrial Accident (IA) procedures.

      There have been no known instances in which AIDS has been transmitted via biting; it is considered an extremely remote possibility.

   f. Good hygiene dictates that food-sharing (i.e., more than one person eating the same piece of food, such as a hot dog, ice cream bar, piece of chicken, etc.) not be permitted. No other mealtime restrictions are necessary. The child with AIDS can use the community table, dishes, glasses, and eating utensils, and be served "family-style" (i.e., from a common serving dish).

2. ENVIRONMENTAL HYGIENE

These practices are applicable for staff who have physical custody of children at DCS offices and for foster care providers.

a. Clean up spills of semen, blood, bloody saliva, urine, feces, or vomit on surfaces such as floors, countertops, bathtubs, etc. with a solution of ten parts water to one part ordinary household bleach. Dispose of the rag or paper towel used in a leakproof container (e.g., a plastic bag) and put in an outdoor trash container. For body fluid spills on bedding, clothing and other washables, see laundering procedures, in "d", below.

b. Baby bottles should be cleaned and sterilized as usual.

c. It is not necessary to wash the child's dishes and utensils separately. Just wash them with hot, sudsy water, rinse and dry thoroughly, either by hand or automatic dishwasher.

d. The child's clothing may be laundered with other family members' clothing, using ordinary laundry detergent, unless it has been soiled by the child's blood, semen, urine, feces, and/or vomit. Use of regular or non-chlorine bleach is recommended, as with any heavily soiled diaper.

   Clothing soiled with body fluids should be washed separately, using normal procedures. Do add 1/2 cup of regular or non-chlorine bleach to the wash cycle. Heavily soiled items (e.g., cloth diapers) may require presoaking.

   Disposable diapers should be placed in a leakproof container (e.g., a plastic bag) and put in an outdoor trash container.

e. Sharing of toys has not been shown to transmit AIDS.

V. PLACEMENT PROCEDURES

A. The incidence of pediatric AIDS has always been and currently remains very low in Los Angeles County. The children at greatest risk are those who received blood or blood products transfusions prior to March, 1985, and infants born to mothers who engage in risk behavior.

Most caseworkers will never have an AIDS, ARC, or HIV positive child in their caseload. For those few cases which will be referred to DCS, the following guidelines for placement have been developed.

B. CHILDREN WITH AIDS

1. These procedures apply to children whose AIDS is in remission and are not actually ill; i.e., they can go to school, on outings, engage in play activities, etc.

2. The first preference is to place these children in foster family homes. Because they are at risk of infection from other children, for their own sakes, they should be placed with the smallest child population possible. With this in mind, a small group home would be the second choice, and a large group home last.

3. No more than one child with AIDS should be placed in any foster care setting, if at all possible.

   A child known to have AIDS should not be referred to MacLaren Children's Center for placement because of the risk to the child from exposure to viruses/germs which may be present in the MCC population. For the reasons explained in step 2., above, an ESC foster home would be the preferred emergency placement resource: It is possible, however, that AIDS could be diagnosed after a child has already been admitted. For this reason, there is a procedure (described in step 4) for placing a child with AIDS out of MacLaren.

4. An appropriate case plan shall be developed in a case staffing by a team comprised of:

   - the caseworker and his/her supervisor;

- staff from the Special Placement Unit (if the child is at MacLaren); and,

- staff from the Foster Care Resources Section. If a foster family home is the placement of choice, the representative shall be the Licensing Deputy, (or designee) who can be telephoned at (213) 418-2016. If a group home placement is planned, the representative shall be the Supervisor, CCIEU, (or designee) who can be telephoned at (213) 418-2850.

In addition, the Director, Juvenile Court Health Services has offered the resources of his medical staff, if needed. This would include participation in the case staffing, talking with potential foster care providers, and visiting the foster care facility to teach AIDS care precautions to the foster care provider. This assistance can be requested by calling the office of Dr. Charles Baker, at (213) 226-8723.

The physician who is treating the child should also be asked for his/her recommendations, if any.

C. CHILDREN WITH AIDS-RELATED COMPLEX (ARC)

Follow the same procedures as with AIDS, described in V.B., above. Although the ARC child is at less risk, the same cautions are advised.

D. CHILDREN WHO ARE HIV POSITIVE ONLY

No special placement procedures are required, unless the child has high-risk behaviors, i.e., those which involve the exchange of blood/semen. In such instances, the case staffing procedure described in step 4., above, shall be followed to determine the appropriate placement setting. These children are asymptomatic and can be placed in any appropriate foster care setting. However, because the child may carry (and therefore be capable of transmitting) HIV, the procedures and information in Part IV., PERSONAL AND ENVIRONMENTAL HYGIENE, and Part VI., SPECIAL CONSIDERATIONS, are applicable.

E. PAYMENT RATES

Because of the special care needed for these children, the F2 rate is recommended for foster family homes.

F. For special procedures regarding completion of the SOC 154/156 and other case recording, see Part VI.A.

G. SHARING PERSONAL AND ENVIRONMENTAL HYGIENE PRECAUTIONS WITH FOSTER CARE PROVIDERS

Part IV. of this Directive, PERSONAL AND ENVIRONMENTAL HYGIENE, is printed separately as Attachment I. When a child who has AIDS, ARC, or is HIV positive is placed in a foster care setting, the caseworker shall photocopy Attachment I and give the copy to the foster care provider.

VI. SPECIAL CONSIDERATIONS

A. CONFIDENTIALITY

1. All DCS case records are confidential. All medical records are privileged information. AIDS, probably more than any other aspect of case information, must be held in the most strictly observed confidence possible. The consequences of casual or inappropriate disclosure can have long-range negative implications for the child, caseworker, foster care provider, and other children in the foster care facility, as well as for the families of all of those people.

2. There are certain parties who will need to be informed that a child has AIDS, ARC, or is HIV positive.

    a. Those who must be told are the caseworker, the foster care provider who has agreed to accept the child for placement, and the child's medical practitioners (including dentist). In addition, the child's parents or legal guardian shall be told (absent a court order to the contrary). The parent/legal guardian shall be offered AIDS counseling. See Part VI.B.

When selecting a foster care placement, do not disclose the child's name until the placement is definite.

NOTE: Tell the foster care provider exactly what the child's status is (AIDS, ARC, or HIV positive), and advise him/her of the need to maintain confidentiality. Do not write these terms on the SOC 154/156. Instead, enter "body fluids precautions." This is necessary to prevent inadvertent and inappropriate disclosure, because these forms may be seen by persons who should not know the child's medical condition.

b. Each person who gains access to this information must keep it in the strictest confidence. The SCSW shall advise all persons who have access to the case of their duty to safeguard the confidential nature of the information.

c. There are other people to whom this information might be appropriately disclosed. Such decisions must be made on a case-by-case basis, after careful and conservative analysis of the person's need to know. Remember, because of the ways the AIDS virus is transmitted, most people who come into contact with the child do not need to know. If in doubt, request guidance from Dr. Baker, Director, Juvenile Court Health Services, or his designee, at (213) 226-8723.

If it is then decided that disclosure seems necessary, the CSW shall petition the court for permission, following standard procedures as described in DH 36400.

An example of a person who might need to know is the principal of the child's school. If it is decided to inform the principal, it shall be done verbally and only to him/her directly. Don't leave a message with the secretary that "so-and-so has AIDS."

Appropriate reasons for informing the principal include: limitations on physical activities recommended by the child's doctor, child is not completely toilet-trained, child has a history of biting or violent behavior.

d. The parents of other children in the foster care setting are not among the parties who have a need to know. They shall not be informed of the health status of the child who has AIDS, ARC, or is HIV positive, except under extraordinary circumstances. In such instances, the CSW shall follow the procedures described in "c", above. An example of when it might be appropriate to disclose is upon learning that high-risk behavior (e.g., blood/semen exchanges) has occurred between the AIDS, ARC, or HIV positive child and another child.

e. The policy of obtaining a court order to disclose to parties other than the foster care provider and the medical practitioner shall be observed unless an emergency condition exists. An example of an emergency would be if the child needed resusitation and a firefighter was preparing to do direct mouth-to-mouth resusitation. It would be appropriate to tell the firefighter that the child has AIDS, ARC or is HIV positive so (s)he can use appropriate infection-control alternatives.

3. Case recording which discloses that the child has AIDS, ARC, or is HIV positive shall be kept in the "Privileged/Confidential Information" envelope used to safeguard all sensitive case information. Forms which would contain the specifics regarding the child's AIDS, ARC or HIV positive status shall contain only a cross-reference to the envelope. See CSH 13140.43 for procedures for separating privileged information. NOTE: CSH 13100 is being revised. The new citation is expected to be CSH 13130.4.

B. COUNSELING

1. Caseworkers should be sensitive to the very likely possibility that the child (if (s)he is mature enough to understand the implications of having AIDS, ARC or being HIV positive), the child's family, and the foster care provider may need counseling.

2. "Counseling" includes group and individual counseling, emotional support groups, one-on-one emotional support, AIDS education, and information services.

   Sexually active gay, bisexual, and non-gay youth may require age-appropriate counseling regarding their sexual practices. When selecting a counseling resource for a gay or bisexual child, special care shall be taken to ensure that the resource can meet the special information needs of that child. Children with hemophilia and children who received blood or blood products transfusions prior to March, 1985 may also need counseling geared to their special circumstances. A third group with possible specialized counseling needs are current and former intravenous drug abusers.

3. Initial counseling shall be done by the caseworker to determine if specialized services are needed, and if so, to identify them and make appropriate referrals.

C. RESOURCES

The following agencies offer a range of AIDS-related services and have agreed to be included in this Directive.

1. AIDS Project/LA (APLA)
   7362 Santa Monica Blvd.
   West Hollywood, California 90046
   (213) 876-8951

   Services available: education, training, referrals to counseling and support groups.

   NOTE: APLA's services are available to gay, bisexual, and non-gay people.

2. Hemophilia Center, Orthopaedic Hospital
   2400 S. Flower Street
   Los Angeles, California 90007
   (213) 742-1000

   Services available: educational counseling and support for children with hemophilia and AIDS, their families and foster caregivers; comprehensive diagnostic treatment and care for children with hemophilia and AIDS.

3. Hemophilia Foundation of So. California
   33 S. Catalina Avenue
   Pasadena, California 91106
   (818) 793-6192

   Services available: no structured program at this time. Call and describe the child's needs and they will try to provide the service. Limited to children with hemophilia and AIDS, their families and foster caregivers.

4. HOTLINES

   a. 1-800-922-AIDS (operated by APLA, Mon-Fri 12:00 noon - 10:00 p.m., Sat and Sun 9:00 a.m. to 3:00 p.m., local time).

   b. 1-800-342-2437 (operated by the Department of Health and Human Services' (HHS) Centers for Disease Control, Mon-Fri 8:30 a.m. to 5:30 p.m., EDT. Provides taped informational messages).

   c. 1-800-447-AIDS (also operated by HHS Mon-Fri 8:00 a.m. - 7:00 p.m. EDT).

   d. 1-800-221-7044 (operated by the National Gay Task Force, NY, Mon-Fri 3:00 p.m. to 9:00 p.m., EDT).

5. Juvenile Court Health Services, DHS
   (213) 226-8723

   Services available: Dr. Baker or his designee will participate in placement staffings, inform and train the AIDS child's foster care provider about the child's needs and AIDS precautions, (see Part V.B.4) and consult as-needed on disclosure of the child's health status (see Part VI. A.2.c).

6. Los Angeles Gay & Lesbian Community
Services Center (LAGLCSC)
1213 N. Highland Avenue
Hollywood, California 90038
(213) 464-7400

Services available: Counseling, information, education, services referrals.

NOTE: The AIDS-related services of LAGLCSC are available to gay, bisexual, and non-gay people.

7. Shanti Foundation
9060 Santa Monica Blvd., Suite. 301
West Hollywood, California 90069
(213) 273-7591

Services available: emotional support groups and one-on-one volunteer support

VII. HIV ANTIBODY TESTING

The policies and procedures described in this Directive apply to children who have already been diagnosed as having AIDS, ARC, or being HIV positive. Caseworkers may also be asked about being tested for AIDS, or having high-risk newborns and other minors tested.

There is a test which detects the presence of antibodies to HIV in a person's blood. There is at this time no test to detect or diagnose AIDS itself. The presence of the HIV antibodies merely means that the person has at some time been exposed to the virus.

No testing of minors may be done without the signed consent of a parent or an order from the court. CSW's may not authorize this test.

"Casual" (i.e., just out of curiosity or groundless fears) testing is strongly discouraged. Most people who have a positive HIV test will remain asymptomatic. They will not develop AIDS or ARC. A small percentage, however, will. Individuals who consider being tested need to consider the effect of the test results, physically and emotionally. Anyone who tests HIV positive should be referred for AIDS counseling and education services.

For those persons who are advised by their doctors to be tested, or for those who have strong reason to believe they have been exposed, anonymous testing is available at the following HIV Antibody Alternative Testing Sites. The tests are free.

1. Edmund D. Edelman Health Center
   1213 North Highland Avenue,
   Los Angeles, California 90038
   (213) 464-7400 Ext 306
   1:00 p.m. to 4:30 p.m. - Information
   (213) 464-7276 10:00 a.m. to 12:00 noon
   Appointments only, Tues-Sat.

2. Long Beach Health Department
   2655 Pine Avenue, Room 111
   Long Beach, California 90806
   (213) 427-7421 - Information
   Walk in - Tuesday 8:00-11:00 a.m.

3. The Center - Long Beach
   2025 East 10th Street
   Long Beach, California 90804
   (213) 434-3089 Information
   Walk in: Tues & Wed., 4:00-8:00 p.m.

Certain newborns (primarily those whose parents are prostitutes/intravenous drug abusers) and other minors are at high risk of contracting AIDS. If there is reason to believe that a child is at risk, the CSW shall ask the physician caring for the child if an antibodies test would be appropriate. If the physician says "yes", the CSW shall ask the parent to sign the consent, or, if the parent cannot or will not, petition the court on a DCS 4225 for permission for the doctor to perform or order the test. No test shall be performed on any child without written parental consent or a court order. The decision to seek the test must be a medical, not a casework, decision.

VIII. QUESTIONS

A. Technical questions about AIDS, ARC, and HIV positives should be directed to the resources listed in Part VI.C.

   Staff are reminded to safeguard confidentiality if specific case circumstances are discussed.

B. Staff requiring assistance in locating or selecting a foster care placement are referred to Part V., PLACEMENT PROCEDURES.

C. Medical questions regarding a specific child with AIDS, ARC, or a HIV positive test may be directed to Dr. Charles Baker, Medical Director, Juvenile Court Health Services, at (213) 226-8723.

D. Questions regarding DCS AIDS policy and procedures should be directed by staff at DCSA level or above to Eileen J. Ritchie, Program Specialist, at (213) 482-2806.

ROBERT L. CHAFFEE, DIRECTOR

RLC:JMI
EJR:cd

Attachment

Lists I, II, III, IV

Attachment I

PERSONAL AND ENVIRONMENTAL HYGIENE

A. There are two primary methods of avoiding the AIDS virus. They are: 1) avoidance of "risk behaviors", and 2) routine hygiene practices.

Since HIV is transmitted most readily via the blood and/or semen of a person with the virus, "risk behaviors" are those which bring a person into intimate contact with these fluids. The most common routes of transmission are: intimate sexual contact; sharing of unsterilized hypodermic needles; blood or blood products transfusions given prior to March, 1985; and, transmission from an infected mother to an unborn or newborn child.

Although HIV is often deadly to its host, outside the body it is actually a fragile virus, easily killed by many common household products, e.g., soap, detergent, bleach, Lysol, hydrogen peroxide, and isopropyl alcohol.

HIV is not transmitted by any form of contact which is appropriate between a caseworker and a child or a foster parent and a child. It is not airborne; therefore it is not transmitted through coughing. It is not transmitted through the saliva or tears of an AIDS patient. Although the virus has been found in these fluids of some patients, the quantity is too small to pose a risk to a well person.

Several long-term studies of health care workers who care for AIDS patients and family members who live with AIDS patients have shown that close, non-sexual shared living arrangements with a person with AIDS have not transmitted the virus. This has been shown to be true even among families with questionable hygiene practices and where no special precautions were taken because it was not known that the person had AIDS. These studies show that the virus is not transmitted from toilet seats, doorknobs, dishes, eating utensils, drinking cups, or swimming pools. AIDS is not spread by talking with an AIDS patient, shaking hands, hugging, casual (as opposed to "deep") kissing, or physical proximity.

Caseworkers and foster care providers observing the simple hygiene routines listed in Part B., can safely care for and be with a child with AIDS, ARC, or a HIV positive test.

It is safe to carry these children in your arms, transport them in your car, hug them, hold their hands, dry their tears, change their diapers, or give them a kiss on the cheek.

B. AIDS is a bloodborne infectious disease. Although it is known that it is very difficult to transmit by non-intimate methods, it is a disease and common-sense precautions are indicated. As with any other bloodborne infectious disease, there are recommended hygiene practices to follow.

They are equally applicable to AIDS, ARC and HIV positive cases.

1. PERSONAL HYGIENE

   a. Do not allow the child to share toothbrushes or razor blades.

   b. Avoid blood-to-blood contact. If you have a skin rash or an open cut on your hands, wear disposable gloves while cleaning up spills of blood, semen, bloody saliva, urine, feces, or vomit.

      If you do have skin contact with these substances, wash the affected areas with soap under running water for 10 seconds.

   c. Wash your hands with soap before and after changing a diaper. Gloves are not needed unless the feces are bloody, in which case disposable gloves may be used. The AIDS virus has not been found in feces itself.

   d. If the child is drooling, wipe up the saliva with a tissue and discard the tissue. Wash your hands with soap.

   e. If the child bites you and draws blood, wash the area immediately with soap and water. As you would with any human bite wound, see a doctor.

There have been no known instances in which AIDS has been transmitted via biting; it is considered an extremely remote possibility.

f. Good hygiene dictates that food-sharing (i.e., more than one person eating the same piece of food, such as a hot dog, ice cream bar, piece of chicken, etc.) not be permitted. No other mealtime restrictions are necessary. The child with AIDS can use the community table, dishes, glasses, and eating utensils, and be served "family-style" (i.e., from a common serving dish).

2. ENVIRONMENTAL HYGIENE

These practices are applicable for staff who have physical custody of children at DCS offices and for foster care providers.

a. Clean up spills of semen, blood, bloody saliva, urine, feces, or vomit on surfaces such as floors, countertops, bathtubs, etc. with a solution of ten parts water to one part ordinary household bleach. Dispose of the rag or paper towel used in a leakproof container (e.g., a plastic bag) and put in an outdoor trash container. For body fluid spills on bedding, clothing and other washables, see laundering procedures, in "d", below.

b. Baby bottles should be cleaned and sterilized as usual.

c. It is not necessary to wash the child's dishes and utensils separately. Just wash them with hot, sudsy water, rinse and dry thoroughly, either by hand or automatic dishwasher.

d. The child's clothing may be laundered with other family members' clothing, using ordinary laundry detergent, unless it has been soiled by the child's blood, semen, urine, feces, and/or vomit. Use of regular or non-chlorine bleach is recommended, as with any heavily soiled diaper.

Clothing soiled with body fluids should be washed separately, using normal procedures. Do add 1/2 cup of regular or non-chlorine bleach to the wash cycle. Heavily soiled items (e.g., cloth diapers) may require presoaking.

Disposable diapers should be placed in a leakproof container (e.g., a plastic bag) and put in an outdoor trash container.

e. Sharing of toys has not been shown to transmit AIDS.

Chairman **Miller**. I am sure I am not going to do him justice, but I feel a little bit like Einstein after the advent of the Atomic Age, when he said that the bomb, in fact, had changed everything but our thinking.

And when I listen to this, I think back ten days ago or two months ago when we were sitting here talking about the budget battles in the Congress, and we are thinking how do we steal another $4 or $500 billion for Title XX and how do we steal some money for Title IV-B to correct the almost criminal situation I think we now have in California with foster care.

Ms. McIntosh, you are telling me that that is really irrelevant at this point. Toddlers and infants used to be the children we could not keep in the system because nobody wanted an adolescent. They were more expensive, they were more independent, and they probably did not like you anyway, and, so, adolescents were right at the bottom. That was the traditional problem and also the notion when we reformed the foster care system: if we simply would put more money into the system, the studies told us, in terms of reunification and preplacement and work with these families, we could return a good number of these children home. You are telling me there is no home to go to for a growing number of children certainly within your jurisdiction.

I am sure your jurisdiction is not outrageous compared to what we can expect in Alameda or may have already. Certainly my colleagues from the East Coast are telling me they are starting to experience this.

It makes you rethink the institutionalization of children; it makes you rethink about the public worry of children, whether it is because of AIDS or because of drugs or what have you; and it makes you obviously rethink the kind of decisions that we would be willing to make.

The question is whether or not the child born with AIDS should be granted an entitlement to those things that are necessary for any victim of AIDS. Let us not limit it to that. I give a lot of speeches about children who end up in outrageous situations through no fault of their own, but you are sitting here along with Dr. Benjamin and Dr. Grossman, who was telling us about children entering the system because their parents took drugs, sexually abused them, and they now are the victims left behind.

The question is, what kind of society are we in terms of the treatment of those children. There are no federal programs for children like that because in the political mind of my colleagues, with all due respect, those children are a little tiny universe. They fall between all these programs.

You are telling me that is a rapidly growing universe.

Ms. **McIntosh**. That is exactly right. I was just coming here from a meeting of the California Welfare Directors Association, where members from all counties discussed this issue among others.

What I was amazed to learn is that not only in the larger urban counties but also in a lot of the smaller counties, we are seeing really growing numbers here, and we now in the state are needing to think through what our policies need to be for these children.

Mr. **Stark**. May I say something?

Chairman **Miller**. Yeah.

Mr. **Stark**. I just wanted to add, Ms. McIntosh, you mentioned blending of funds. Remember that you are dealing with a guy named Swoap who, in my mind, has the mind of a piranha and the heart of a Doberman Pinscher, he wrote the book on block grants, which is nothing more than a buzzword for this present Federal Administration to put them all together and then cut them.

From a practical standpoint, is wise to keep some of these programs separate? At least when the Administration tries to eliminate their funding, the constituents support them, the Congress, by trying to fund them individually, is going to end up getting you some money.

If you let the Swoaps and the Reagans of the world have their way, we will turn it all over to the states and the counties. I just wanted to interject that. As I think you are right, if we give you the money to do it, I think it will be wonderful, but it is a real dangerous world.

Ms. **McIntosh**. Yes, your point is well taken. We suffer greatly now from block grants that have taken place in the past.

I think the concern is that there be mechanisms within the funding streams that permit the use of these funds to funnel towards the victims and not to have the victims have to match only a single category in order to receive a single slice.

Mr. **Stark**. I agree with that.

Ms. **McIntosh**. I appreciate your comments. Thank you.

Chairman **Miller**. Dr. Benjamin?

Dr. **Benjamin**. It may even go a little bit further because even if some money were there and could be granted to many counties, those counties who have already seen that this issue in health is a major one and have decided to use those monies in that arena, may have already approached the Gain limit and they have got big problems. You cannot put anymore in it.

So, what do we do with the money if we even get it?

Chairman **Miller**. Yes?

Mrs. **Boxer**. I just think that this panel has been an outstanding one for all of us, and I think when you are talking about an emergency situation, that we have got to do something about the Gain issue, with all due respect.

Epidemics do not obey the laws of tax initiatives.

Dr. **Benjamin**. Or economics.

Mrs. **Boxer**. And we had better come to grips with that as a society or we will not have a society.

I have a couple comments and a couple questions. I am a fairly optimistic person, and I have been trying to find some little thing to cling to here, and the only thing that there is to cling to is AIDS is a preventable disease. You are the second physician who has drummed that into my mind; the other one being Art Ammann. I do not know if you know him. He is a pediatric AIDS doctor, who is now doing research on vaccines.

So, knowing that, it seems to me that we have got to separate this problem into two. One is the people who are already exposed and the horrible problem that this presents us here, we cannot do anything to unexpose them. We did not know anything, we have got to deal with that, and Pete Stark and his committee are going to have the outflow of that and how we will fund this and so will the Budget Committee.

And, then, the other is preventing it, and we know now that condoms prevent AIDS. If they are used properly and if they work, and it is really hard for politicians to talk about things like this, and you do not understand . . .

Dr. **Benjamin**. But I think we do. I think we do.

The Chairman **Miller**. We develop an adult stammer. They did not know they had it their whole life, but apparently it was there.

Mrs. **Boxer**. So, the thing is we have to stop having that and we have to get—I know I have seen it happening in the churches and I see it happening in the schools. It is evident. So, it seems to me that we have to have a vaccine, and the only vaccine is education—period. That is it. That is a vaccine. Education prevention. So, we have to have a program to do that. If we are going to get anything out of this, it is certainly that because, if we do not do that, then the society will be overrun with this thing.

Could you respond to that? I mean, I think you need television because you can reach, as you point out, these kids through the schools, but you need to have a massive television campaign because everybody watches television.

Dr. **Benjamin**. If I may and then Ms. McIntosh.

Mrs. **Boxer**. Yes. You all may respond.

Dr. **Benjamin**. I think you all are absolutely right. The mass media is the only way that we can do anything and had not just as a small example this prevalent study that we have done, that we did here in this county, had that not gotten TV coverage, we would not have done anything.

I am not as optimistic as you would even like me to be because what I look at as an epidemiologist are surrogate markers of sexual behavior, and what we have seen here is . . .

Mrs. **Boxer**. What do you mean?

Dr. **Benjamin**. What other markers of sexual behavior can we look at besides AIDS? Okay. Syphilis. In the last year, in this county, hepatitis B, which is transmitted exactly in the same way except there is some household transmission of Hep-B, there is not household transmission of AIDS, has increased by forty-two percent. Syphilis, up twenty-one percent. Gonorrhea, up fourteen percent. If this was the stock market, I would say buy.

When you look at the percentage in terms of infectious syphilis of those who are gay or bi-sexual, in 1983, twenty-nine percent of our syphilis cases in this county were gay men. Last year, it is down to nine percent. What does that mean in the face of an increase of twenty-one percent in syphilis, it is increasing the general heterosexual population. The message is not getting out. Not getting out.

Mrs. **Boxer**. But it got out in the gay community and you have dramatic decreases in these other areas.

Dr. **Benjamin**. It got out and we had outstanding——

Chairman **Miller**. On that point, should we be impressed in terms of viewing what is possible, should we be impressed in terms of the educational programs that have gone on within the gay community?

Dr. **Benjamin**. Absolutely. Absolutely. The problem, if I may—yes.

The Chairman **Miller**. When we see the risk that is involved and we see the declines in these numbers and studies, that should tell us that education, in fact, can be accomplished. Is that what you are saying?

Dr. **Benjamin**. What—the comment—if I can translate that comment a little bit into something that may be a little more useful, is if we wait to count cases, we are at least five years too late, at least five years too late, and that is why the problem reached the magnitude it did in the gay community, because we did not know what was going on. We know now and it is the gay community that has led us to that.

We now have an opportunity to prevent further spread and right now, as you say, we are at about the same point in this epidemic now as we were with polio in the late forties and early fifties. We knew very well the epidemiology of the disease. We knew how it was transmitted. My parents refused to let me go swimming in public places during the summer in the forties and fifties, and we are now waiting for another Jonas Salk to come along, but until he or she comes along, Jonas Salk, we have only got education, and it has been effective. It has been effective in the gay community and I was astounded at how effective it was just this last month here. It works.

We have got to really use that, and, again, now,

Chairman **Miller**. Obviously, there have been numerous successes, but I guess I am just so cynical after the recent episode of the Congress dealing with drugs in our society and what happened before and after the election. But I think back to an effort when the President of the United States was running for re-election, he brought together, I think it was something called, the Tuesday Club. He brought together the very best minds in public media to sell him to the American public and to win that election, which was a strategy that we as politicians look to in terms of where he went for his advice. My concern is that the Congress, in a fit of emotionalism, can vote a billion dollars in education this year and then, in a fit of political reality, that the Congress looks back six months and decides next year that that billion dollars was a waste, nothing happened.

How do we develop a national curriculum, a national effort. It is not a question of whether we want to do it in Wyoming or L.A.; it is a question that it must be done. If we are not getting hysterical and—your testimony is based upon reality, and I just worry that the billion dollars gets kind of——

Dr. **Benjamin**. In my political naivete,

Chairman **Miller**. You know, like Contra money, everybody sucks it off and nobody gets a rifle or something.

Dr. **Benjamin**. In my political naivete, about six or nine months ago, I decided that since this country was launching into this war on drugs, spearheaded by the Reagans, I might write a letter to Nancy Reagan, and I did, and the letter said, gee, I think you are doing a real good thing, and this is some evidence that we have about how AIDS is transmitted. Do you not think it is high time to incorporate this in your message. You have not heard it? It is time and, yeah, I will not go into the rest of what you have not heard.

Mrs. **Boxer**. Mr. Chairman?

Chairman **Miller**. Yes.

Mrs. **Boxer**. In raising this very question with the panel of doctors in Los Angeles, their comment was that they were backing Henry Waxman's budget which comes down just below a billion, about half of it for education and the other half research and also a little piece for some model programs and treatment, and a piece for drugs, making sure that we get the drugs out to those that need them.

They made the same point you did. We have got to be real careful that we do not just throw money at this thing and then have a bad reaction, and they suggested, and it is in the form of a bill by Jerry Lewis, a national commission on AIDS, which would oversee this thing.

I at first thought, you know, not another commission. You think you are doing something when you have a commission, but I really think that this makes good sense, and we will take a look at that when we put together our recommendations.

Could I ask one question?

Chairman **Miller**. You may ask all the questions you want.

Mrs. **Boxer**. The last thing I wanted to comment is empowering the women to say no, and I agree with you, but I would hope that that is not all that we put out on that message.

Dr. **Benjamin**. Please do not misconstrue that.

Mrs. **Boxer**. We have got to be responsible.

Dr. **Benjamin**. Absolutely.

Mrs. **Boxer**. Because the woman just cannot sit there by herself and say no, we really need to support that and the men are going to have to work to take the responsibility and not just let the women take it.

Dr. **Benjamin**. Absolutely. I did not mean to suggest that.

Mrs. **Boxer**. I know you did not, but——

Dr. **Benjamin**. That is just one other avenue.

Mrs. **Boxer** [continuing]. I am supporting what you are saying.

Chairman **Miller**. We were obviously discussing the need, and the flip side of that should not be that the male can be a jerk, you know, and we were a little worried about that.

Mrs. **Boxer**. So, we want to see some priorities.

My last point regards this hemophiliac situation, could you put into numbers for me, you said that seventy to ninety percent of hemophiliacs have been exposed because they have those transfusions before we knew how to make the blood supply safe?

What does that mean in terms of numbers?

Mr. **Williams**. Well, if the numbers that I have given are correct, there are about 20,000 hemophiliacs in the United States. Our figures would tend to say a higher proportion, towards the ninety percent rather than the seventy percent figure, of those individuals who were born prior to 1986 have received the concentrates which have the virus and have, therefore, been exposed to the virus.

So, you can use Dr. Benjamin's five year model. If you look forward five years, you can expect that whatever the attack rate is, (we are now into an area that is not administrative and I am not an expert,) but the attack rate will determine the question of how many of those patients will, in fact, develop the disease.

It is going to be a large number, and the point of the financial side, as I have indicated, is you must add those costs on top of the costs of treating the underlying disease. Frankly, there is not a lot of information known on how do you treat hemophilia and AIDS together and what it costs. That is where the cost implication will be.

Mrs. **Boxer**. Well, I think where this impacts on my chairman's field of interest here is on children because if we do have these drugs that prolong life, which we want to see, and these people have babies, people with AIDS having babies with AIDS, I just think it is a profound situation for us.

Mr. Chairman, I do have to go. As usual, you have provided us with a format that is exceptional. Thank you.

Chairman **Miller**. Thank you. Thank you.

What is the stigma involved if the hospital is going to be designated either formally or informally as an AIDS hospital?

Mr. **Williams**. Well, thank you for asking for that question.

Chairman **Miller**. Whether a children's hospital or a general hospital.

Mr. **Williams**. If I could respond to, first of all, Dr. Grossman's point. I do not agree with Dr. Grossman on this point. I think Children's Hospitals, at least, and the facilities that care for children see AIDS children as people who are sick; as individuals who are the reason we as institutions exist. We treat them at Children's Hospital at Stanford and most Children's Hospitals see these children as patients with major infectious disease problems and we would treat these kids like other patients.

So, I do not think that the concept of setting up a separate system makes sense for children, I think the numbers may be an issue here. There are smaller numbers of children that are likely to come down with this disease for all the reasons we have said and childrens hospitals can accommodate them probably.

I think the issue is really getting a stable funding source so that their care can be paid for within the current environment of health care financing.

Chairman **Miller**. I understand that, but when we are dealing with a certain level of ignorance within the public as to the nature of AIDS, and a certain level of hysteria as a result of that, what are the ramifications if people start saying to their doctors, I do not want to be admitted to that hospital?

Mr. **Williams**. Well,

Chairman **Miller**. Especially if the hospital has patients that are losers in terms of financial reimbursement, what if the hospital makes just a simple economic decision, we better not expand our involvement with this caseload, we will not take that caseload, because we are starting to hear from doctors that their patients do not want to have surgery in this facility or they do not want their children or parents or what have you at this facility?

Is it realistic? Is it going to be a problem?

Mr. **Williams**. I think it is an issue. First of all, education becomes the answer to the issue. We know, at least so far as any research has been able to be done and research has been done very intensively among hospital employees to see whether it is possible for this disease to be transmitted other than by the major ways discussed earlier.

There has not been, to my knowledge, a single case of a hospital staff member turning antibody positive with the AIDS virus as a result of caring for either children or adults. We need to get that message out to parents, in the case of children, and to the population at large, that the disease is preventable, that you are not going to catch it by having these people in your apartment or by having them in the bed next to you. Children's Hospitals, in particular, care for large numbers of patients who have some sort of a contagious disease or infection. That is part of the nature of pediatrics, and we have mechanisms for controlling the problem of infecting others—patients or staff.

So, I think that there should not be a stigma, but I think it is a real issue at this point until the education level becomes higher.

Chairman Miller. You obviously have seen the stigma within another part of the social services systems in terms of foster care, with people making a decision that they are not going to participate.

Ms. McIntosh. That is exactly right. What we are seeing is trying to educate our prospective foster parents and group home operators and so forth that they can care for these children, safely for the children and safely for themselves.

Chairman Miller. Let me ask you since we have the chief of insurance here—the reaction that you are getting from a potential foster parent is not an unrealistic reaction. If I think I am going to bring a foster child home or adopt a child and put that child on my health care policy and that is going to lead to cancellation of my policy, along with the coverage for my children and my spouse, it is a rational decision for me not to become an adoptive parent or a foster parent.

Ms. McIntosh. Well, I think if we look at the added impact of social isolation, the education system being somewhat reluctant in some cases to take the children, all of those kinds of impacts, then we see the one compounding the other, and we see families who really do want to care for these youngsters, for example, and who may be willing to take some risks in terms of offering physical care, not being able to withstand the social pressure and the financial realities that these children may present.

Mr. Stark. Chairman, yield? You make a good case for the counties to start risk pools. Insurance companies are not going to do it. They will exclude it and risk pools would be the answer. Say it is an epileptic or somebody with diabetes who has trouble getting insurance. It seems to me the fair way is for everybody to chip in with their fifty cents a month on their own policy and pay for these risks, because if they do not pay for it, the price is going to go up anyway. We will pay for it through our real estate taxes or we will pay for it through higher costs for our own insurance.

Chairman Miller. Well, thank you. Thank you very much for your participation in the panel and with the committee. Certainly, this committee and the entire Congress is going to continue to need your additional help.

Pete, thank you for sitting in with us this morning. Thank you.

Mr. STARK. Thank you, Mr. Chairman.

CHAIRMAN MILLER. The next panel that we will hear from will be Dr. Sylvia Villarreal, who is from the Department of Public Health and a Physician Specialist, City and County of San Francisco; William Barrick, who is a Program Manager for the AIDS Project here at Alta Bates/Herrick Hospitals; and Marcia Quackenbush, who is Coordinator of Youth and AIDS Prevention Project, University of San Francisco, AIDS Health Project in San Francisco.

Come forward, and we will recognize you in that order.

Is John Schwartzberg here? Dr. Schwartzberg is supposed to be here.

Again, we want you to proceed in the manner in which you are most comfortable. To the extent that you want to summarize, I would appreciate that. Also, to the extent that you want to comment on something you heard before, where you think there needs to be a correction or an elaboration to complete this record, feel free to do that also.

Dr. Villarreal?

STATEMENT OF DR. SYLVIA VILLARREAL, DEPARTMENT OF PUBLIC HEALTH, PHYSICIAN SPECIALIST, CITY AND COUNTY OF SAN FRANCISCO; SAN FRANCISCO DEPARTMENT OF HEALTH AIDS MINORITY TASK FORCE; BOARD OF DIRECTORS, CALIFORNIA CHILDREN'S LOBBY, SAN FRANCISCO, CA

Dr. VILLARREAL. As a pediatrician and a Hispanic, I am very concerned about ethnic and racial minority children and their risk of AIDS. My area of expertise is children in the marginal society. Of the total 423 pediatric AIDS cases reported as of January 26, 1987, 60 percent are black children, and 23 are Hispanic. That is 93 percent of all the children with AIDS are children of color.

These data are even more startling when one realizes that the black population comprise eleven percent of the total U.S. population and Hispanics only seven percent. Most of the infants and children are infected during pregnancy. It has been found that 86 percent of these children with AIDS have at least one IV drug using parent.

In New York, 20 to 30,000 children have been born to IV drug using mothers between 1982 and 1986. These are Puerto Rican and black babies. If we assume a conservative, thirty percent rate of transmission from infected mothers to their babies, there are estimated to be 6,000 HIU infected infants in the New York-New Jersey area. In San Francisco, in 1987, we predict using similar calculations 14 babies will be born to high risk IV drug using mothers.

San Francisco's numbers are relatively small compared to New York. We only have six children, three are black, one Hispanic, and two children with transfusion recipient AIDS. How do we explain some of these relatively low numbers in contrast to the New York-New Jersey? Perhaps we in San Francisco are enlightened. We have organized quickly enough in the marginal society to prevent the transmission of AIDS. It could be the natural delay of the transmission to the West Coast or it could be that we have just been damn lucky.

An AIDS advisory committee has been organized to advise the Director of Public Health in San Francisco on AIDS-related conditions and problems, and mental health issues of the black, Hispanic and Asian communities. Currently, the Department of Public Health is conducting outreach and funding to people of color addressing education and prevention, especially our IV drug using population.

The startling disparity in the representation of minority children with AIDS reflects the real basic problems of the marginal society. Poverty, low education, and drug abuse. I believe that the following policy issues need careful scruting and attention.

First, the medically-fragile child. It is critical to state that the HIV infected child be included in the definition of the medically-fragile child. As you know, that means children who are similar to chronically ill infants or low birth weight infants, and that their care is very specialized, and their health easily deteriorates.

If these children become medically-fragile, then parents and foster parents can get at least a little bit more money for their care. Further research needs to be done to define both in-hospital and home placement needs and costs.

Currently, New York City is hospitalizing HIV positive children, who are not clinically ill, because of the inability to secure adequate placement. Reasonable effort in compliance with S.B. 14 should be made to ensure that parents, both natural and foster, have adequate training and supervision for those children who go to their homes.

The second problem is the AIDS child in foster care. There are two major problems facing the social service departments in the disposition of children at risk AIDS, and one is antibody testing of the at-risk children, and, again, these at-risk children are children of color, and the second is placement of HIV positive children.

We must adhere to rigorous standards to protect the rights of the child and the parent, in order to decide to test or place the child.

Ethical issues of confidentiality must be addressed before any testing is allowed. The rights of the natural parents must be upheld by the existing laws, and this includes visitation rights, due process, and reunification if at all possible.

The third and really the most critical item is prevention and education of the marginal child and family. Racial, ethnic, and culturally specific and sensitive education must be financed and targeted to the communities of color.

Previous models, it was talked about by the first panel, used for gay populations may not be appropriate or sensitive to the needs of diverse people. Hopefully, we can use what has been done in the gay community and work in conjunction with gay leaders to educate minority populations.

Mr. Miller, as you know, there is much stigma associated with AIDS as a gay disease in minority communities and homophobia is rampant. We must educate people that AIDS is a non-sexist and non-racist disease and it affects everyone.

I will briefly mention that an important group to target is the minority adolescents, especially the high risk teen pregnancy, especially in the Black and Hispanic community.

I thank you for your generous time and attention. It is now noon. It is only through our concerted effort on the local, state, and federal level that the epidemic can be stopped. Perhaps the problems of the poor may never be alleviated, but AIDS-related illness in poor children must be prevented.

Thank you.

[Prepared statement of Sylvia Villarreal M.D., follows:]

PREPARED STATEMENT OF SYLVIA F. VILLARREAL, M.D.

It is indeed an honor to present before you and your esteemed committee on the important topic of AIDS and the child. I will focus my discussion on the area of my expertise: "Children of the Marginal Society."[1]

As a Pediatrician and a Hispanic, I am very concerned about ethnic and racial minority children and their risk of AIDS. Of the total 423 pediatric AIDS cases reported as of January 26, 1987, 60% of the children are black, and 23% Hispanic.[2,3] These data are even more startling when one realizes that the black population represents only 11% of the total U.S. population, and Hispanics represent only 7%. Most of these infants and children became infected during pregnancy, it has been found that 86% of children with AIDS have at least one IV drug using parent.

Peter Selwyn of Albert Einstein School of Medicine, estimates that 20,000 to 30,000 babies, the majority black and Puerto Rican, have been born in the New York area to IV drug using mothers between 1982 and 1986. Assuming a 30% rate of transmission from infected mothers to their babies this conservative estimate suggests some 6,000 high risk infants are probably infected with HIV.[4] In San Francisco, John Newmeyer, has used similar calculations to predict that 14 infants will be born to IV drug using mothers here in 1987.[5]

The number of children in San Francisco infected from 1981-1986 have been:

Table 1.

AIDS IN CHILDREN 0-12 YEARS	WHITE	BLACK	HISPANIC
CHILD OF HIGH RISK/AIDS PARENT	0	3	1
TRANSFUSION RECIPIENT	2	0	0
HEMOPHILIAC	0	0	0

(Data obtained by the San Francisco AIDS Activity Office, 1987)

These relatively low numbers are in stark contrast to New York and New Jersey's large and growing childhood population with AIDS. Perhaps we in San Francisco have organized quickly enough in the marginal society to prevent maternal transmission of AIDS. It may be natural delay of transmission, or it could be that we have just been lucky. An AIDS Advisory Committee has been organized to advise the director of Public Health on AIDS-related health and mental health issues of the black, Hispanic, and Asian communities. Currently, the Department of Public Health is conducting outreach and funding to people of color addressing education and prevention, especially in the IV drug using population.

The disparity in representation of minority children with AIDS reflects their living in the marginal society of poverty, low education and drug abuse.[6,7] I believe that the following policy issues need careful scrutiny and attention if we are to adequately address the problem of AIDS in minority children:

I. The medically fragile child

II. The AIDS child in foster care

III. Prevention and Education of Marginal Children and Families

I. The Medically Fragile Child

The HIV-infected child should be included in the definition of the medically fragile child.[8,9] Children with HIV-infection are similar to severely premature infants or low birth weight babies in that their care is specialized and their health easily deteriorates. Further research needs to be done to define both in hospital and home placement needs and costs. Currently, New York City is hospitalizing HIV positive children not clinically ill because of inability to secure adequate placement. Reasonable efforts, in compliance of SB 14, should be made to insure that parents (natural or foster) have adequate training and supervision for those children who can go to their homes.

II. AIDS Child in Foster Care

There are two major problems facing social service departments in the disposition of children at-risk for AIDS. One is the antibody testing of at risk children, and the second is placement of HIV-positive children. Rigorous standards must be established to protect the rights of the child and parent in any decision to test or place a child. Ethical issues of confidentiality must be addressed before indiscriminate testing is allowed. The rights of the natural parent must be upheld by the existing law, this includes visitation, due process and reunification if at all possible.

III. Prevention and Education of Marginal Children and Families

Racial, ethnic and culturally specific and sensitive education must be financed and targeted for the communities of color. Previous models used for gay and white populations may not be appropriate or sensitive to the needs of diverse peoples. Hopefully, we can use what has been done in the gay community and work in conjunction with gay leaders to educate minority populations. Unfortunately much stigma is associated with AIDS as a "gay" disease in the minority community.[10] We must educate that it is a nonsexist and nonracist disease that attacks all.

An important group to target is the minority adolescent.[11]

Thank you for your generous time and attention. It is only through concerted effort on the local, state and Federal level can this epidemic be stopped. The problems of the poor may never be alleviated, but AIDS related illness in children must be prevented.

BIBLIOGRAPHY

1. Villarreal S.F. Current Issues in Hispanic Health. Vol. VIII: Hispanic Health Issues. Report of the Secretary's Task Force on Black & Minority Health. U. S. Department of Health and Human Services. January 1986. pp. 11-42.

2. Confronting AIDS Directions for Public Health, Health Care, and Research. Institute of Medicine. National Academy of Sciences. National Academy Press. Washington, D.C. 1986 pp. 61-62.

3. Acquired Immunodeficiency Syndrome (AIDS) Weekly Surveillance Report--United States AIDS Program. Center for Infectious Diseases. Centers for Disease Control. January 26, 1987.

4. Houston-Hamilton A. A constant increase: AIDS in ethnic communities. Focus A Review of AIDS Research. Vol 1, No. 11. A publication of the AIDS Health Project, University of California San Francisco. pp 1-2.

5. Correspondence John Newmeyer. Haight Ashbury Free Medical Clinic. October 20, 1986.

6. Children in Poverty. Congressional Research Service. House Committee on Ways and Means. May 1985.

7. Hispanic Children in Poverty. Congressional Research Service, Report No. 85-170 EPW September 13, 1985.

8. Halfon N., Villarreal S.F. Toward a definition of medically fragile infants. *Child Health Policy Board.* March 7, 1986, Children's Research Institute of California.

9. Jameson E.J. Medically fragile infants in the foster care system. *Youth Law Center*. January 30, 1986.

10. Bakeman, R., Lumb J.R. Jackson, R.E., Smith D.W. 'AIDS risk group profiles in whites and members of minority groups. *NEJM* 1986;315:3.

11. DiClemente RJ, Zone J., Temoshok L: Adolescents' and AIDS: A survey of knowledge, beliefs and attitudes about AIDS in San Francisco. *Am J Pub Health* 1986;76:1443-1445.

The **Chairman**. Thank you.
Mr. Barrick?

STATEMENT OF WILLIAM BARRICK, R.N., M.S.N., PROGRAM MANAGER, AIDS PROJECT, ALTA BATES/HERRICK HOSPITALS, BERKELEY, CA

Mr. **Barrick**. Good afternoon.

My name is Bill Barrick, and I am Program Manager for the AIDS Services here at Alta Bates/Herrick Hospitals. I am a registered nurse. I have a Master in Science in nursing and administration.

I have worked in the epidemic for four years, first at San Francisco General Hospital, and most recently here at Alta Bates/Herrick.

In my mind, the issues of AIDS, which relate to your committee's work, are divided into four large areas: Vertical transmission of HIV from mothers to the unborn child, the risk to both mother and child, risks to young children existing in transfusions or Factor 8, the effect on children and adolescents whose parents or parent become infected and symptomatic of AIDS, and, fourth, the potential for AIDS infection among adolescents experimenting with sex and drugs.

I want to take just a few minutes to look at those and give you some scenarios based on our experience. With regard to vertical transmission of HIV, the first concern certainly would be to identify the women who are HIV infected and counsel them with regard to pregnancy or continued pregnancy. The models developed for genetic counseling will play a large part in future programming.

Our high risk pregnancy program has begun testing women and of twenty-eight already tested, two have been found positive.

With regard to AIDS in newborns at Alta Bates in the last few months, four children have been born infected with HIV. The all too frequent principles have been an IV drug using mother who is discharged or leaves against medical advice within forty-eight hours of delivery, and the child remains in our nursery or who is transferred to the intensive care nursery at Children's Hospital, Oakland, while kicking the mother's habit.

The child will stay for several weeks. During the first week, the mother may visit twice and during the second week, once. After the second week, the mother disappears and our social work team frequently then takes over and they eventually proceed to seeking legal conservation and medical fosterage.

In support of Dr. Grossman's concerns with the California legislation on confidentiality of HIV results, we have specific problems in this area with regard to the fact that in California, it is actually illegal to inform the medical foster parents of a child's HIV positivity. That has created tremendous educational difficulties which, in proactive programming here in Alta Bates on education of prospective medical foster parents, we have been able to ameliorate somewhat and raise the willingness of foster parents to care for these children.

But a particular concern also are the Hispanic and black mothers in whom the incidence of HIV virus is already nine to fifteen times higher than among whites.

The issues of transfusion and Factor 8 are now controlled, although cases with long latency periods will continue to emerge for some time. The general trend is downward for this population.

I have grave concerns for a population of children and adolescents of two previously unidentified risk groups. It is my belief with support from East Coast communities with similar demographics to the Alameda, Contra Costa Counties, that there will soon be a burgeoning population of suburban married men and women with AIDS.

There is a substantial but uncountable population of men in our society whose internal identification as heterosexual but whose behavior is functionally bi-sexual. These are men who have live in suburban middle-class communities where they are family men with wives and children. They also come into urban areas on occasion or frequently to have homosexual, sexual experiences. These men are at risk to develop AIDS in an environment where their wives and children are unaware of their risks.

Among the wives and mothers of these families are women who are sexually active, unknown to their families. These women will be at risk to acquire AIDS from men who are infected and pass the virus sexually. The effect on such family groups is and will be devastating.

Finally and most frightening of all is the certainty of a burgeoning adolescent population with AIDS. For those of us who are parents and for those of us who are not, but remember our own teenage years, the feelings of immortality and invulnerability which go with those years will be familiar.

Discussions of the morality of teaching safer sex and safer shooting must be put aside in favor of a category to save the lives of our children. We join with Dr. C. Everett Koop in recommending curricula in our schools to meet this terrifying threat.

We acknowledge with Dr. Paul Volberding at San Francisco General that the public sector can no longer support the weight of the epidemic alone. Alta Bates has elected to meet the needs as we see them with a comprehensive program, including an AIDS out-patient clinic, education, services, and case management and social services under one roof, known as ACCESS, which stands for AIDS Care, Community, Education, and Support Services.

However, it is just as sure that the private sector cannot support the economic challenges of the epidemic without help from government. Case management, proactive social service programming, education, and similar services are not adequately supported by the reimbursing agencies to which private health care currently has access.

We look to government for policy encouragement and fiscal support. I would just like to respond to a question, Mr. Miller, you asked Mr. Williams of Stanford Children's Hospital with regard to stigmatization of health care facilities, providing AIDS services.

That is certainly something that we here at Alta Bates had to consider and discuss as we began to consider this issue. I think that I can identify a number of processes that has led to a willingness to do this. One has been the extraordinary solidarity of our medical staff behind the issues of caring for persons with HIV infection, and the rather impressive efforts of our public affairs people in presenting this to the community, and also the enormous support that we have been given by Berkeley City and Alameda County in making our entrance into this area.

[Prepared statement of William Barrick follows:]

PREPARED STATEMENT OF WILLIAM BARRICK, PROGRAM MANAGER FOR AIDS SERVICES AT ALTA BATES/HERRICK HOSPITALS

My name is William Barrick, Program Manager for AIDS Services at Alta Bates/Herrick Hospitals. I am a Registered Nurse and have attained a Master of Science in Nursing with an Emphasis in Administration.

In the past few months, the effect of Human Immunodeficiency Virus (HIV) infection among women has begun to manifest as babies born at Alta Bates Hospital with signs of the disease AIDS. Of 4,266 births at Alta Bates in 1986, four recently delivered babies have been infected. The eventual number of affected infants is impossible to determine at this time; the numbers are not yet sufficient for statistical treatment. However, of twenty-eight women thus far HIV antibody tested in a new program developed by our High Risk Pregnancy Program, two pregnant women have tested positive. When our experience is viewed against the background of obstetrics on the Eastern Seaboard, the outlook is frightening. Certainly we agree with Doctor C. Everett Koop that education is the only effective vaccine we currently have.

The concept of "risk groups" which was a feature of AIDS epidemiological conceptualization was only accurate as long as the proportions of those infected remained the same. With the recent increases noted in heterosexual transmission, the concept of "risk behavior" has replaced that of "risk group." To teach and plan effectively, it must be understood that AIDS infection is the result of certain behaviors, not sexual orientations. The Committee will be concerned most with women who have AIDS as a result of intravenous drug use, the children they bear and infect, and the adolescent who experiments with sex and drugs. The best preventative medicine we know is to teach the "at risk" individual how to avoid infection. I will continually stress the importance of education to women and adolescents. Of particular importance is the creation and expansion of services reaching Hispanic and black mothers--the incidence of HIV infection in their children is already nine to fifteen times higher than among whites. Another education issue is the need for specialized teaching models appropriate to the needs of the illiterate adult and teenager whose ability to respond to most of our slide and overhead shows, pamphlets, and PBS programming is greatly reduced.

The impact on clinical services before, during, and after birth is already being seen in New York and New Jersey. California, being two to three years behind the East Coast in numbers, has a unique opportunity to prepare. Our prenatal services must work to identify HIV positive mothers and advise them using many of the models developed for genetic counseling. Our perinatal services must take the appropriate precautions, as suggested by the Centers for Disease Control, to protect the health care team during and after delivery of the infant. And our postnatal services must be prepared for lengthy follow-up of the mother compromised by intravenous drug use and HIV infection.

The impact on clinical services for infants and children will be more serious. Infant services will be seeing unknown numbers of children with chronic and mortal disease. The danger of live-virus immunization of children with AIDS may cause such diseases as measles, rubella, and mumps to reappear among these children. Frequent office visits to pediatricians for close follow-up will become routine. Inpatient treatment of infections will be far more frequent in this group. Acute care hospital admissions for diagnosis and treatment of neurological manifestations of AIDS will be more frequent. The Centers for Disease Control have recommended that children with HIV infection be cared for by pediatricians knowledgeable in the management of AIDS. Knowledgeable and experienced pediatricians must be identified and supported through the creation of a new pediatric sub-specialty.

The impact on home health and social services will be extreme. Case management will be needed to deal with such issues as parenting skills, AIDS infection control in the home, logistical support needed to secure appropriate medical follow-up, fosterage, medical fosterage, AIDS education of parents and foster-parents, counseling, substance use rehabilitation, vocational training, and the like. Only through such home care and social services can scarce resources be conserved and used most efficiently. If the impact on home health and social services is not extreme, the load on hospitals will be back-breaking.

Important as the infant and mother issues are, the potential for AIDS in the adolescent population dwarfs all other child-related AIDS issues. There is a real and immediate need to act to protect children and adolescents at the time of life when many experiment with sexuality and drugs. Arguments concerning the morality of "safer sex" and "safer shooting" education must take second place to realism and the imperative to save lives. We join with Dr. Koop in urging AIDS education in the schools, and in any other possible young person's forum. The teenager is a difficult person to convince. Those of us who are parents, or remember our own adolescence, know the feelings of immortality and invulnerability which attend those years. Expert planning will be needed to reach our children and convince them to protect themselves from this tragic disease.

In response to the AIDS crisis, Alta Bates has taken the innovative case management approach and is providing comprehensive services in the epidemic. The ACCESS staff networks with the other resources of Alta Bates/Herrick Hospitals, and with community and government organizations to provide high quality assessment, planning, treatment, referral, monitoring, and advocacy services. Medical services include HIV antibody testing and counseling; "worried-well" primary care services; primary and consultative medical care including current research protocols, and research protocol services for community physicians. Nursing services include triage, a nursing intake clinic, a treatment room for intermittent infusions of medications and fluids, and nutritional counseling. Social work services include assistance with income programs, residence referrals, entry into social and practical support programs, and counseling services. ACCESS provides community education. ACCESS networks with Alameda County facilities, Childrens Hospital and Medical Center of Oakland, and other Northern California facilities to provide an integrated network of resources. Alta Bates and Childrens Hospital are currently reviewing services to HIV infected mothers and children to plan the most effective intervention to meet their special needs.

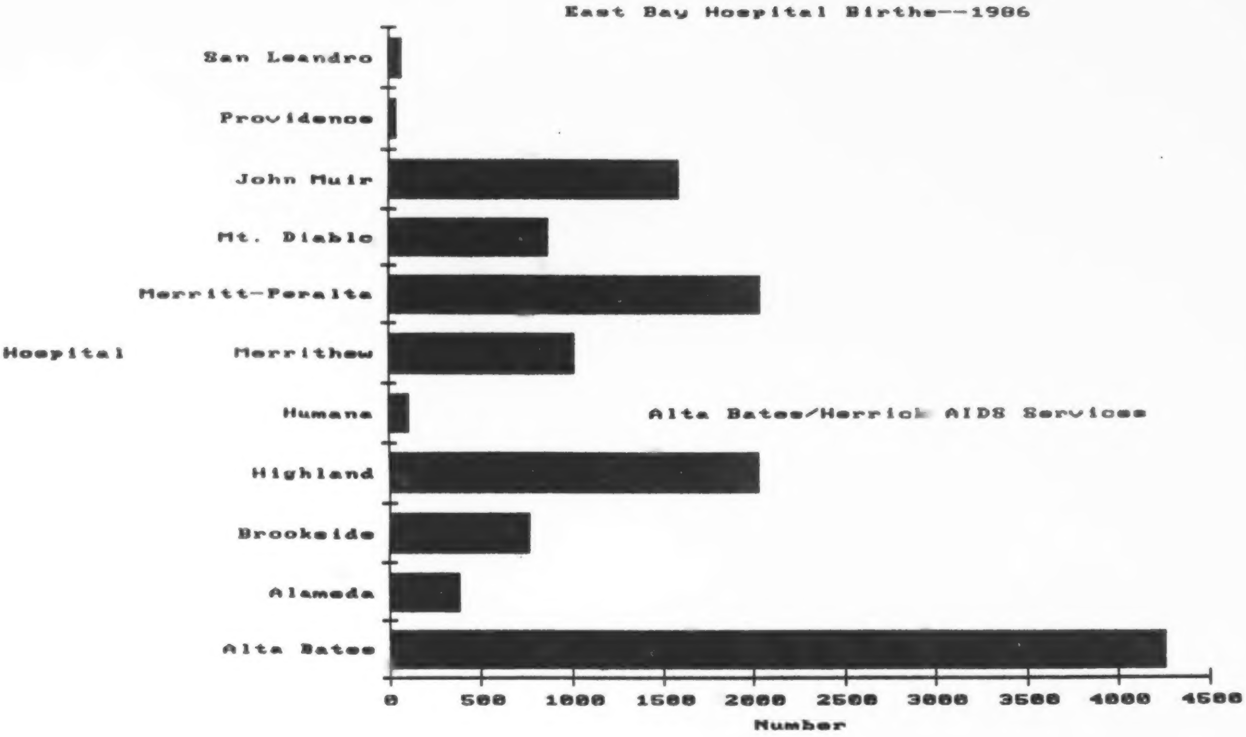
Any projection of costs of hospital care for children would be premature since the California experience thus far includes only 24 children. The adult cost of care ranges nationally from $60,000 to over $140,000 per case. The greatest determinate in the cost equation is the number of hospital days consumed per case. Home health and Case Management have proven themselves cost effective, cost containing, and more emotionally supportive and sensitive than hospital care in the San Francisco adult model. Of particular value have been home health interventions in cases of neurologically impaired clients, an outcome of AIDS which recent literature shows children will not be spared.

Savings accrued through proactive use of home health and social services to adults, compared to admission to an acute care hospital without such services, range from 50 to 75%. There is every reason to believe the same will be true of the pediatric population.

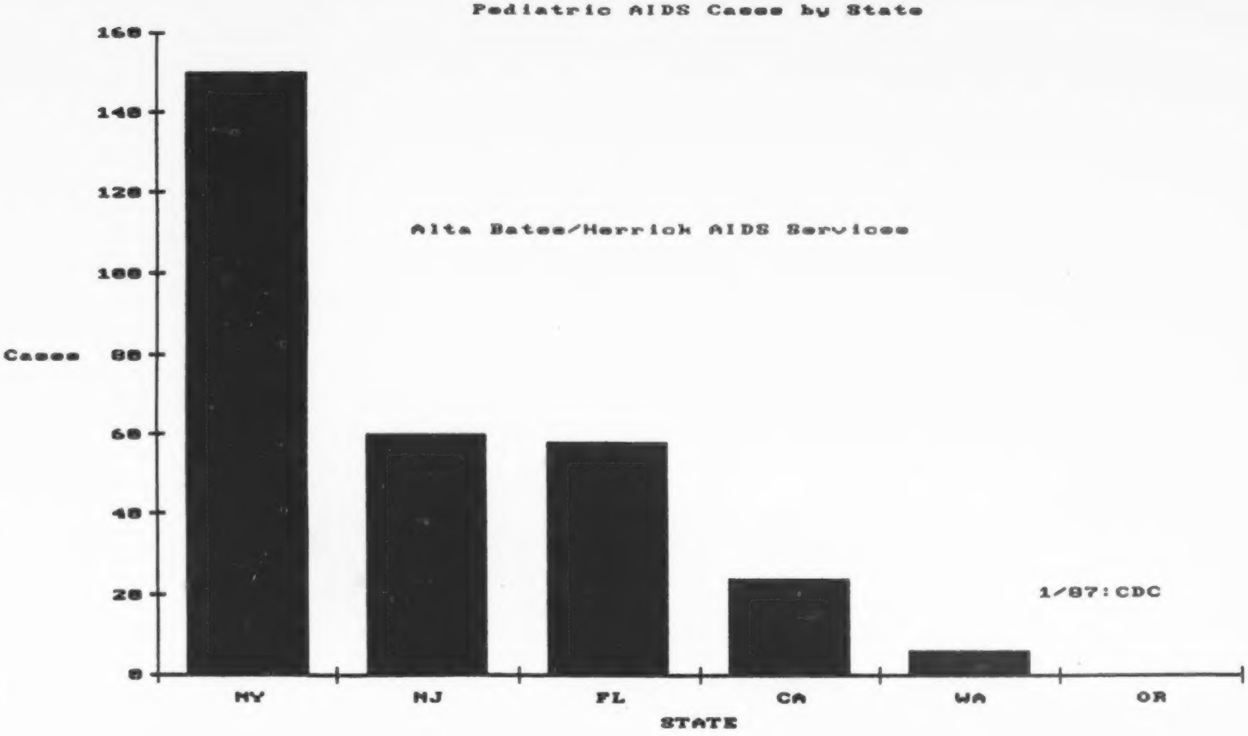
The AIDS epidemic is producing the greatest strain on service provision by the health care industry in living memory. Alta Bates/Herrick Hospitals is dedicated to meeting the demand with high quality, cost-containing, comprehensive, and integrated services. The case management approach has proven itself to be the most effective and patient-rights-oriented approach to management of large-scale services.

We look now to Congress for guidance, policy, and subsidy.

ACCESS
AIDS Care, Community Education, and Social Services
A member of the Alta Bates Health System
2640 Telegraph Avenue
Berkeley, CA 94605
[415] 540-1870



Alta Bates/Herrick AIDS Services

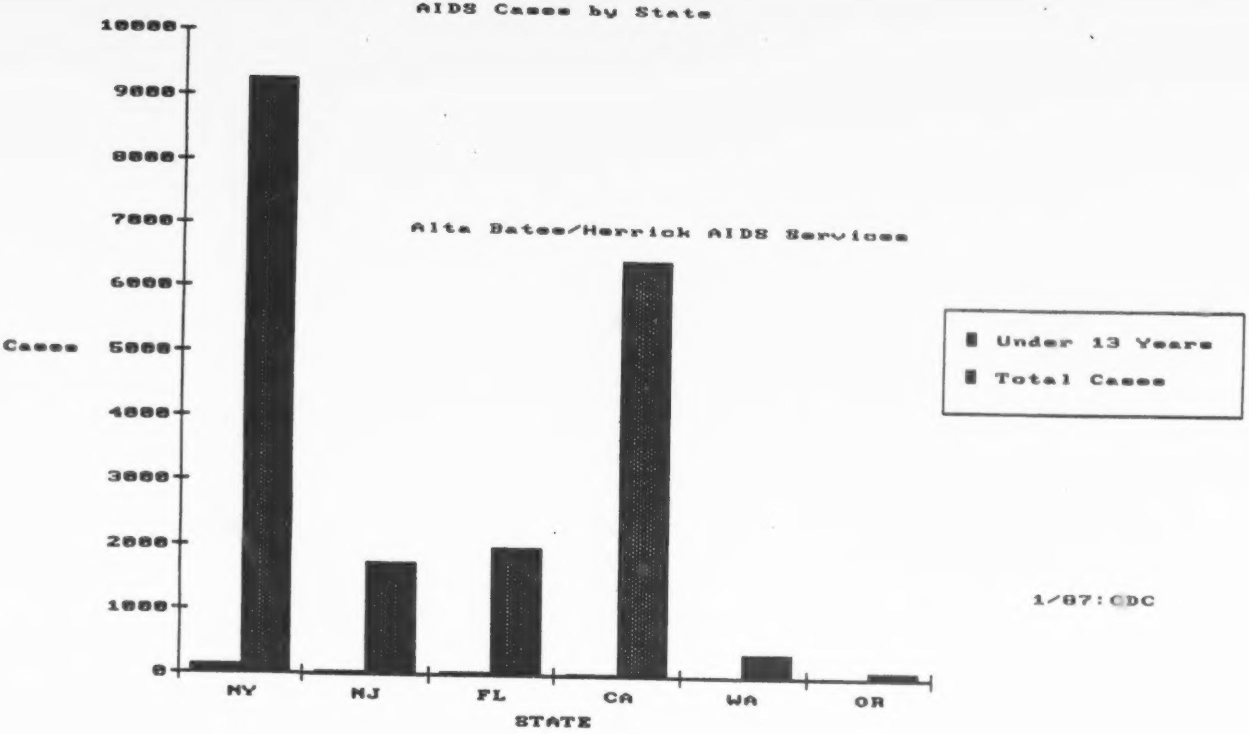


Pediatric AIDS Cases by State

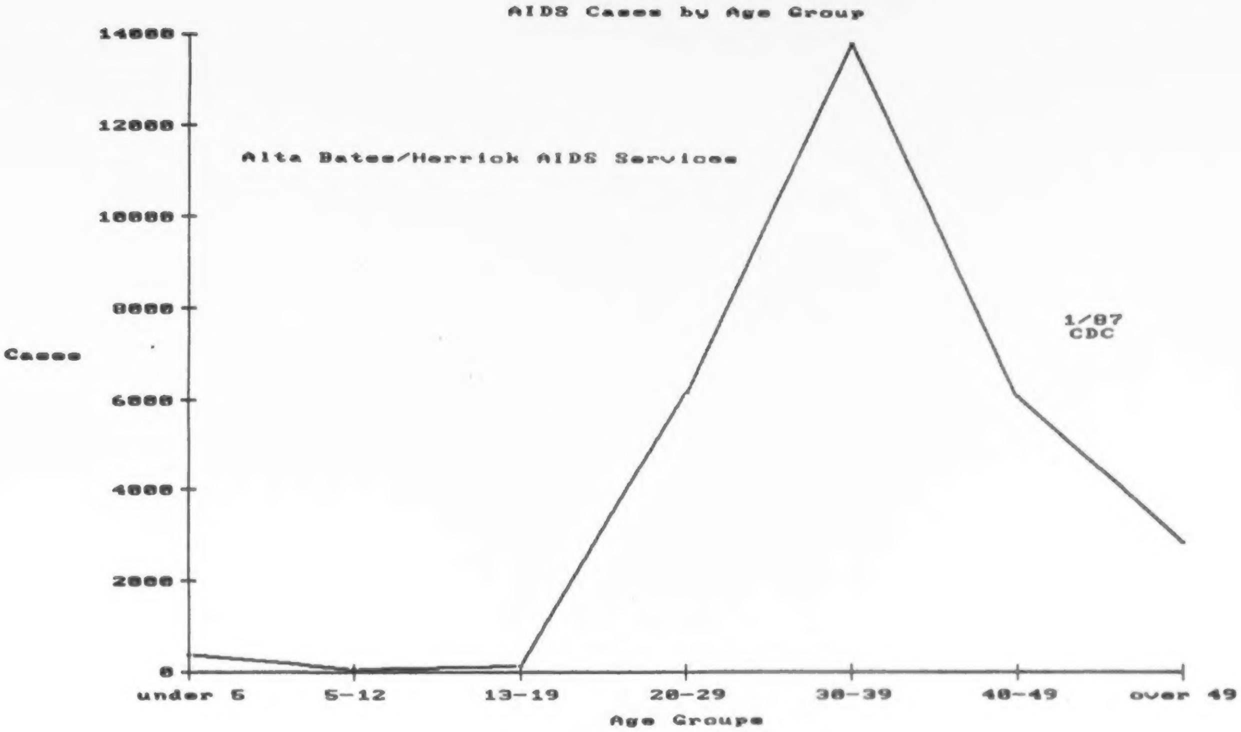
Alta Bates/Herrick AIDS Services

1/87:CDC

AIDS Cases by State



1/87: CDC



AIDS Cases by Age Group

Alta Bates/Herrick AIDS Services

1/87
CDC

Chairman **Miller**. Thank you.

Ms. Quackenbush?

STATEMENT OF MARCIA QUACKENBUSH, M.S., COORDINATOR, YOUTH AND AIDS PREVENTION PROJECTION, UNIVERSITY OF SAN FRANCISCO AIDS HEALTH PROJECT, SAN FRANCISCO, CA

Ms. **Quackenbush**. Thank you for inviting me to speak before you today on this important concern.

I was invited because I am the primary authority of teaching aids, which is a curriculum for high school students on AIDS. Also, I worked with the Youth and AIDS Prevention Project

Chairman **Miller**. You are going to have to speak up. We cannot hear you.

Ms. **Quackenbush**. It sounds loud from here.

I work at the University of California AIDS Health Project as coordinator of the Youth and AIDS Prevention Program, and I also do private consulting on AIDS-related educational concerns.

Today, I am going to talk specifically about curriculum issues for teenagers and younger children. The need for AIDS education for teenagers has received a fair amount of attention, and I think we are seeing a general trend toward school-based AIDS prevention.

The rationales for providing this education of teens seems to be gaining greater acceptance. They are addressed in more detail in my written testimony, but briefly include sexual activities of teenagers, which can put them at risk, drug use behavior, the epidemiology. We know now that we have a long incubation period for this disease. There are 6,000 plus people diagnosed in the twenty to twenty-nine year old age range. Certainly some of these were infected as teenagers.

So, the argument that teenagers do not get AIDS certainly is not accurate. The great majority of teens that are not currently sexually active certainly will choose to be so at a future time. They could use the prevention information now, and, finally, I think teenagers are quite interested in receiving AIDS-related education.

Some people have suggested we should emphasize abstinence as the only acceptable means of AIDS prevention for young people. I will point out that fifty percent of our high school students today have already made the decision not to be abstinent. If we do not give them full and complete information about AIDS prevention, we are being neglectful.

I also want to remind you that twenty-five percent of the students will drop out before high school graduation. There is a need for community-based as well as school-based prevention programs.

There are also compelling reasons to provide AIDS education to younger children. This issue is more controversial and has received less endorsement generally. So, I would like to take this opportunity to advocate for such programs.

Some points to consider. As Dr. Grossman mentioned, if we do not begin AIDS education until the middle of high school, a small but significant number of children will already be engaging in risk behavior before they receive the prevention information.

Two. Young children need help understanding the concept of "not casually transmitted." The diseases that young children are familiar with are, for the most part, very easily transmitted and they have a hard time understanding sometimes that they are not at risk to contract AIDS in their normal affairs with playmates, students, and their families.

Information as essential as AIDS prevention needs to be repeated over a period of time for it to be fully comprehended. We expand our opportunity to do this and to provide this information and education effectively by starting early.

Children have a natural interest in the events around them, including the AIDS epidemic, and they deserve answers to those questions. Furthermore, fifth and six graders may actually be more receptive to this information, including understanding their responsibilities for prevention, than older children in seventh and eighth grades, for example.

Many children, especially in high incidence areas, have friends or family members at risk for or diagnosed with AIDS. They need the sort of understanding and support that can come from classroom education about the disease, and we also have the possibility of children appearing on school campuses with AIDS or HIV infection, and I think having school education helps the school and students prepare for that.

Finally, basic AIDS education in an integrated program of family life and health education offered over the course of a student's school career also helps place it in its proper perspective for the student's life. We do want our children to have careful regard for and understanding of this terrible disease. We do not want them to be unnecessarily obsessed or panicked by it.

In terms of the content, the key for young children is developmentally appropriate materials. We are not suggesting that we go into first grade classes and discuss anal intercourse, but we can discuss this issue of easy to transmit/difficult to transmit, beginning with first and second grade.

One known risk of AIDS transmission, which Jean McIntosh mentioned earlier, is that children are being sexually molested by HIV-infected adults. Such cases have been reported and there are instances where infection has resulted.

In this light, another approach to AIDS prevention would be the promotion of programs to prevent child sexual abuse and aggressive intervention in cases where abuse is reasonably expected.

There are some school programs teaching children assertiveness skills, how to say no, that they have the right to privacy with their body.

Finally, I have reviewed today some of the reasons AIDS education is appropriate and necessary in schools. I think support of developing programs and materials, evaluations of the effectiveness of these materials and teacher training are probably our greatest needs at this time. We will also need to educate local communities about these concerns and enlist their cooperation in carrying out AIDS education programs.

Finally, Ms. Boxer earlier said she was looking for some place to hold on, some beacon of hope, and what I would say is I think in terms of educational programs within the schools, there are some very specific, very concrete things that can be done that can be carried out that will be effective.

I appreciate your attention today and look forward to your support in our further endeavors.

Thank you.

[Prepared statement of Marcia Quackenbush follows:]

Prepared Statement of Marcia Quackenbush, M.S., Coordinator, Youth and AIDS Prevention Program, AIDS Health Project, University of California, San Francisco

This testimony addresses the education needs of children and youth regarding AIDS. Since the issues and concerns of adolescents in this regard are quite different from those of younger children, these two groups will be discussed separately.

I have worked in the filed of youth and AIDS prevention since March, 1984, when I was hired as coordinator of the Youth and AIDS Prevention Program. I continue in that position at present, and also do private consulting involving teacher training for AIDS education and related concerns. I was the primary author of *Teaching AIDS*[1] the first professionally published, nationally distributed curriculum on AIDS. I have trained teachers, school and program administrators, employees of the criminal justice system, nurses, psychologists, physicians, counselors, street workers, and other youth service providers. I have also provided direct services to a variety of youth, including runaways, street youth, male and female juvenile prostitutes, incarcerated juveniles, IV drug users and public and private school students.

ADOLESCENTS

Concerns about the possibilities of AIDS transmission among teenagers were almost non-existent three years ago, but more recently much greater attention has been focused in this area. Popular press reports on the issue now appear with some regularity.[2] Research on seropositivity and transmission among high-risk teens is also being pursued.[3] Our knowledge about AIDS and adolescents is preliminary, however there are many compelling reasons to provide AIDS prevention education to teens.

Rationales for Providing AIDS Education to Teenagers

1. The current practice of high-risk sexual activities by teenagers.

An unknown number of young people are presently engaged in the very high risks of unsafe male-to-male sexual encounters and unsafe sexual encounters with IV drug users.

Among enrolled American high school students, 50% of teenage women have had sexual intercourse, and 16% of these report four or more different partners.[4]

Further, there are over one million teenage pregnancies annually (about 3,000 conceptions daily), and an estimated one in seven teenagers currently *has* a sexually transmitted disease.[5]

The same activities which cause unwanted pregnancy and most sexually transmitted diseases can also transmit AIDS.

2. The current practice of IV drug use by teenagers.

There are no national statistics on IV drug use among American teenagers. In high schools, estimated use of substances likely to be taken intravenously in some instances include:

Heroin—1.3% (over 200,000 students)
Other opiates—10% (two million students)
Stimulants—35% (seven million students)
Cocaine—16% (over three million students)[6,7]

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[1] Quackenbush M, Sargent P. *Teaching AIDS: A Resource Guide on the Acquired Immune Deficiency Syndrome*. Santa Cruz, CA: Network Publications, 1986.

[2] Kids and Contraceptives. *Newsweek*. February 16, 1987: 54ff.

[3] Richard Brown, MD. San Francisco General Hospital, Department of Pediatrics. Personal communication, February 1987.

[4] Alan Guttmacher Institute. Teenage Pregnancy: The Problem That Hasn't Gone Away. New York: Alan Guttmacher Institute, 1981.

[5] Lumiere R, Cook S. *Healthy Sex*. New York: Simon & Schuster, 1983.

[6] Johnston LD, O'Malley PM, Bachman JG. *Use of licit and illicit drugs by America's high school students 1975-1984*. U.S. Department of Health & Human Services, 1985; DHHS Publications No. (ADM) 85-1394.

[7] These figures are from a 1984 survey and do not include the increase in cocaine use associated with the rising popularity of crack.

3. The likelihood of future risk behaviors.

The great majority of students *will* engage in sexual activity at some future time in their teen or adult life. Providing prevention information *before* they run the risk of infection is a matter of simple logic.

4. The current epidemiologic trends.

As of January 26, 1987, only 131 (less than 1%) of US AIDS cases were among 13-19 year olds. However, 6198 (21%) were among 20-29 year olds.[8] Current reports suggest a mean incubation of about five years for AIDS. Certainly many of those individuals diagnosed in their early twenties were originally infected in their teens.

5. Teenagers *want* AIDS education.

In a recent report, 87.6% of 1,326 high school students surveyed agreed, "It is important that students learn about AIDS in Family Life Education cinfected in their teens.

5. Teenagers *want* AIDS education.

In a recent report, 87.6% of 1,326 high school students surveyed agreed, "It is important that students learn about AIDS in Family Life Education classes." [9,10]

6. Teenagers often have unnecessary fears about the possibility of casual transmission of AIDS.

In the survey mentioned above, only 68% of respondents were aware that AIDS could not be spread by casual contact.

Concepts

There are four essential concepts to teach teenagers about AIDS.

1. AIDS is a viral disease, not a gay disease.
2. AIDS is not easily transmitted.
3. Under the proper circumstances, *anyone* can contract AIDS. (The specific circumstances for transmitting AIDS should be described.)
4. You can protect yourself from AIDS. (The specific means of protecting oneself, including the use of condoms, should be described.)

The best means of teaching these concepts will vary by locale and student age. Suggestions that educators should emphasize abstinence as the only acceptable prevention strategy my be well-intentioned, but they are misguided. Fifty per cent of our high school students already do *not* practice abstinence. Failing to offer full and explicit prevention information to teenagers would be negligent under the circumstances.

Materials

Teaching materials appropriate for high school students are now beginning to appear, and some innovative approaches to AIDS education have been reported.[11,12,13] Materials specifically for middle school students are scarce. Evaluation projects, looking at the effectiveness of teaching materials, would be most useful.

A selection of teen-focused videos on AIDS prevention is currently available.[14] *Teaching AIDS*, the curriculum I co-authored, is a good general source offering basic information about AIDS and suggesting several possible approaches to the material.

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[8] Centers for Disease Control: AIDS Weekly Surveillance Report, January 26, 1987.

[8] Centers for Disease Control: AIDS Weekly Surveillance Report, January 26, 1987.

[9] DiClemente RJ, Zorn J, and Temoshok L. Adolescents and AIDS: A survey of knowledge, attitudes, and beliefs about AIDS in San Francisco. *American Journal of Public Health 1986;* 76:1443-1445.

[10] These results are entirely consistent with my own anecdotal experience teaching high school classes about AIDS. The presentation is usually enthusiastically received.

[11] High School AIDS Education: Seattle program targets student editors. AIDS Information Exchange: US Conference of Mayors, December, 1986; 1-3.

[12] Gordon B. Rap Songs About AIDS—S.F. tries to reach youth. *San Francisco Chronicle*, February 10, 1987:8.

[13] Licata SJ. New York City Department of Health Peer-Generated educational material on AIDS for youth. Abstract submitted for the 1987 National Lesbian & Gay Health Conference/Fifth National AIDS Forum.

[14] Currently available titles include:

AIDS: What Everyone Needs To Know. Churchill Films, 662 North Robertson Blvd., Los Angeles, CA 90069-5089.

Sex, Drugs and AIDS. ODN Productions, Inc., 74 Varick Street, Suite 304, New York, NY, 10013.

AIDS in Your School. Peregrine Productions, 330 Santa Rita, Palo Alto, CA 94301.

The AIDS Movie. New Day Films, 22 Riverview Drive, Wayne, NJ 07470-3191.

AIDS: Acquired Immune Deficiency Syndrome. Walt Disney Telecommunications and Non-Theatrical Company, 4563 Colorado Blvd., Los Angeles, CA 90039.

However, because of the sensitive and sometimes controversial nature of AIDS education, as well as local variations in student concern and comprehension, it is expected that specific programs will vary by community. Each school district will need support to plan and design its own locally relevant approach to AIDS education. This process has been followed, fairly successfully, by the San Francisco Unified School District, which received federal funds to hire a health educator to develop materials for their schools.[15]

Special Populations and Concerns

This testimony has addressed school-related AIDS education issues. Many other youth concerns must also be considered. Some 25% of our youth will drop out of school before graduation. Certain groups, including juvenile prostitutes and street youth, are generally at much higher risk than high school students to contract and transmit AIDS. Ethnic minority youth may respond better to community-based education programs than school-based. Institutionalized and incarcerated adolescents will need specialized programs. In considering the needs of adolescents, it is important to remember that school programs, while essential, are not a complete answer.

YOUNGER CHILDREN

The issue of planning AIDS prevention programs for younger children is controversial, but I wish to advocate strongly for consideration of such programs.

Rationales for Providing AIDS Education to Younger Students

1. If AIDS education classes do not begin until middle or high school, a small but important percentage of students will already be engaging in risk behaviors before the program is offered.

2. Many younger children, especially in areas with high incidences of AIDS, are concerned that they might contract the disease. They need help understanding the concept "not casually tranmitted."

3. To be effective, information about AIDS transmission and prevention must be repeated, in depth, over a span of time.

Constance Wofsy, M.D., a leading AIDS researcher, has stated that even adults cannot fully comprehend the impact of AIDS, and the means of transmission and prevention, until this has been reviewed in some depth at least five times.[16] In circumstances as serious as these, we must endeavor to provide the soundest foundation possible for clear and responsible understanding about AIDS, and providing this information throughout a child's school career is one way to achieve this goal.

4. Younger students are naturally curious about AIDS, and fifth and sixth graders may actually be more receptive to AIDS prevention information than older students.

Stories about AIDS surround us. Children hear adults discussing AIDS and sometimes have normal and healthy questions about the disease. The pre-teen is often more willing to listen to education on sexual issues than the adolescent, who is coping with personal feelings about his or her own sexual development. In this more "clinical" atmosphere, a fifth or sixth grader might better understand the concerns about AIDS, and his or her own ultimate responsibilities for preventing transmission may be clearer.

5. Many children, particularly in high incidence areas, have friends or family who have been diagnosed with AIDS, and their needs for understanding among their peers are significant.

The goal of AIDS education for young children is not only prevention, but also understanding. We know of several instances in which children had experienced the death of a relative by AIDS, but felt unable to mention this to schoolmates or teachers for fear of how the information might be handled. In addition, children's natural curiosity and concern about death is raised by tales of AIDS, and these emotional issues can be constructively addressed in an appropriate classroom setting.

6. Placing AIDS education in an integrated program of family life and health education, offered over the course of a student's school career, also helps place it in its proper perspective for the student's life.

Quite possibly, AIDS will be with us beyond the turn of the century. Unnecessary panic and obsessive worry are not legacies we wish to leave our children. In providing sound AIDS education, we not only seek to teach our children prevention, but hope that they can see AIDS as a serious aspect of their complex world, one which they can respond to rationally and conscientiously.

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[15] Cheri Pies, MPH. Personal communication, February 1987.

[16] *An Epidemic of Fear: AIDS in the Workplace.* Video produced by Pacific Bell, 1986.

Content

Specific concepts to teach young children have not been widely established. I include some preliminary suggestions.

Grades 1 and above

1. There are different ways diseases are passed. Some are passed easily, and others are difficult to pass.

Most if not all of the diseases children are familiar with are easily transmissible (colds, chicken pox, measles). They are not usually aware of diseases that are "hard to get."

2. AIDS is a serious disease.

3. AIDS is a difficult disease to pass. You cannot get AIDS from the kind of contact you have with friends or parents.

Grades 3 and above

4. Many people have died of AIDs. This is one of the reasons it is such a serious disease.

This material would best be offered in the context of other lessons on life and death, possibly including discussion of other serious diseases, other ways of dying, etc.

Grades 5 and above

5. Explanation of sexual contact and drug use as modes of AIDS transmission.

Again, this material will make better sense if it is offered as part of a fuller program on sexuality and drug-related issues.

6. Explanation of ways people can prevent AIDS transmission.

AIDS education for younger children must be developmentally appropriate and should be integrated into other health and family life lessons. AIDS can be presented as one of many issues, and details can become more specific as children mature and have both the interest and comprehension necessary to understand the materials.

Materials

At present, there are no widely available materials for elementary aged classes. The states of Texas and New York are reportedly addressing or planning to address AIDS issues as early as third grade.[17] The development of resources for these younger children will be a challenging task. Funding should be provided in support of such work, as well as for evaluation of effectiveness of materials. As with middle and high schools, it will be most useful to provide basic resources, then offer assistance to different areas in adapting the materials to make them locally relevant and appropriate.

Special Concerns

One real risk of AIDS transmission for children is that of being sexually molested by an HIV-infected adult. Such cases have been reported, and there are instances where infection of the child has resulted. In this light, another approach to AIDS prevention with children would be the promotion of programs to prevent child sexual abuse, and aggressive intervention in cases where abuse is reasonably suspected.

In conclusion, I would like to express my appreciation to the members of the Select Committee for their time and attention, and their valuable consideration of these important issues. Some very good work in youth education on AIDS has been started, and much remains to be done. I trust these trends will be supported and expanded in the future.

ATTACHMENTS

1. *FOCUS: A Review of AIDS Research*. February, 1987: Volume 2, Number 3.
2. *Teaching AIDS: Resource Guide on the Acquired Immune Deficiency Syndrome*.

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[17] New State Guidelines OK'd on Sex Education. *San Francisco Chronicle*, February 12, 1987: 8.

Chairman **Miller**. Thank you.

I think it is fair to assume that some of the time frames certainly within the political arena in our society are starting to look at AIDS and deal with it, are going to start to collapse, and let me just ask with respect to curriculum.

In terms of your involvement with curriculum, if we lay this on to the school systems, since that is where a good portion of young people are, how confident are you that (1) the school systems can absorb this and properly make the transmission of that information to the young people. And (2) to the extent to which that becomes consistent with what else we are trying to do in the community, whether at large or in specialized communities, how do we make sure that this is what we wanted to do, and how do we make this compatible? I think we are going to have a very short time frame before we make the decision. I am not asking for a guarantee that it is a hundred percent compatible, but it seems to me that there are a number of different arenas where education has to take place. Again, I go back to some of our experience in trying to transmit—I mean, we had a thousand different messages going out last year to young people about how they were going to deal with drug use in our society, and I am not sure that there was a realistic credible picture presented on how you would accomplish that if you were an adolescent or if you were an adult.

One minute, you see flashes of a lot of celebrities dying and the next minute you are told you can handle it if you have just got the guts to say no, and the other one says, well, maybe you cannot. Everybody was sort of taking the ball and running in whatever direction their ideological point of view was coming from or where the funding was.

I am not interested in remaking that experience.

Ms. **Quackenbush**. I think your suggestions or comments are certainly appropriate. One of the things that was pointed out to me recently is that we have a lot of AIDS experts on one hand saying this is what we need to do with young people and then we have sex education experts who do not know as much about AIDS but know more about what is developmentally appropriate, and we only need to bring those people together.

I had a meeting a couple of days ago with a woman named Debra Haffner, who works for the Center for Population options and she said she actually has a great plan for this, which is to have a national meeting pulling together sex education experts, AIDS and medical public health experts, talking about what are the messages we need for what ages, at what point are they developmentally appropriate, to come up with some generalized guidelines and then to get a program to persuade community organizations and school districts to endorse this so that we can have a more centralized message.

I do think that that—I think that needs to be done, and I think the thing about AIDS, which is important, is that the message is relatively simple. How you actually accomplish that may be more difficult, but AIDS is a preventable disease. AIDS is a viral disease, not a gay disease.

Anyone can contract AIDS under certain circumstances. You can prevent AIDS. It is not casually transmitted. These are the kinds of concepts we need to teach. They are simple concepts. So, I think in many ways, we actually have a lot more hope in teaching about AIDS than about drugs where things can be a lot more complex.

Mr. **Barrick**. The expression of those concepts, however, can be relatively variable, and we have to look at multi-lingual models, multi-cultural models, and very seriously look at the issue of illiteracy in adult and teenage population in this country, who are not going to understand our typical slide-audio-dog-and-pony shows that most of us are used to putting on.

So, those issues will emerge, I think, in the next year, and already I see some funding, particularly for multi-cultural and multilinguistic models.

Ms. **Quackenbush**. Yeah. I think the thing to remember about particularly school-based AIDS prevention is that this is only one piece of it. The encouraging thing is I think it will be relatively inexpensive compared to community-based programs. I have done a fair amount of work with high-risk youth. I have worked with IV drug users, incarcerated juveniles, juvenile male and female prostitutes. Very, very difficult. Very expensive population to work with.

When you are talking about case loads for the amount of money, it is a lot more expensive than doing school-based programs. This is not a complete answer, but it is only one piece of it. I think it is something we can carry out, and I agree with your comments.

Mr. **Barrick**. Marvelously enough, I know parents who are now organizing block parties for their kids and the neighbors' kids to talk about safe sex. So, the word is getting out there. The issues that I have in that area, of course, are the consistency of the message.

Chairman **Miller** That is my concern.

Mr. **Barrick**. But it is promising.

Chairman **Miller** Dr. Villarreal, let me ask you something, and, Ms. McIntosh, if you would just listen, because I would like your comments on this, and see if I am correct.

One of the clear differences that we see in adult AIDS and AIDS among children is the minority make-up of the children's population, and what appears the fact that they are coming from highly distressed families because of the use of drugs, primarily. Historically, if my limited involvement in foster care system tells me anything, those children will have a much more difficult time being assimilated into either social services or into adopted families or foster families, the traditional mode that we are going to reunify them with their families a few months later, after some kind of public care, does not look like it is going to work. I just wonder, to the extent that you are calling our attention to this, are you starting to see this change in the make-up in terms of the increase in minority population and the infants and toddlers, is that happening in Los Angeles?

Dr. **Villarreal**. Yes.

Chairman **Miller**. And is that one of the reasons why you are not going to get the placement? I do not know what the make-up was in 1950 of foster parents, but I suspect it was fairly white and I suspect it was also in 1960 and 1970 and probably in 1980. And we also know that there were a whole slew of minority babies that are left behind in that entire system because very few people will provide foster or adoptive care for those children. So, Dr. **Villarreal**. One of the issues that we brought up in Children's Lobby with——

Chairman **Miller**. Your warning, Dr. Villarreal, warning is already actively engaged, your system of foster care or institutionalization or public care of these children in Los Angeles.

Dr. **Villarreal**. Absolutely. Children of color are over-represented in the child welfare system and particularly in the foster care system, and, so, among the infants and toddlers that we see waiting for placement, we see a very high incidence of children of color there.

Chairman **Miller**. Which historically has been a problem.

Dr. **Villarreal**. That is correct.

Chairman **Miller**. But, now, children of color with AIDS or drug-related problems or experience during birth or what have you.

Dr. **Villarreal**. Yes. That is correct.

Chairman **Miller**. The political system has not responded to that particular mix terribly well in this country.

Dr. **Villarreal**. That is why I presented the unification model. It is very avant garde and working with foster kids, I ran a clinic just for them, and I tried as best as possible to keep some of these marginal people, the marginal families, together.

Now, you have to pump in a lot of money to keep mom and the kids together. You have the IV using mother who may be infected, you have a child who may be HIV positive, if possible, to keep them together and, of course, keep close tabs, we had them in the clinic almost every week, we had social services involved.

It is sort of like mothering the mother to mother the child.

Chairman **Miller**. But that is an entirely different structure than we currently have in the system today. To keep the single drug dependent mother who may or may not have AIDS with her child, who may or may not have AIDS or may or may not be drug dependent, is a different system. Just in terms of their ability to live and strong sense of family, however restricted, is not present in the system today.

Where would you go if you were going to provide that care, if you were going to refer those people?

Ms. **McIntosh**. Exactly. I wanted to

Chairman **Miller**. In New York, they go to the Martinique Hotel, for homeless families.

Ms. **McIntosh**. We have got——

Chairman **Miller**. Then, they have three strikes.

Ms. **McIntosh**. In Los Angeles County, one of the critical issues that we are facing is in those situations where we feel that we want to try to provide the same service that Dr. Villarreal is discussing, which is keeping the mother and child together, we simply do not have the resources and are not able to blend the funds in order to provide that——

Chairman **Miller**. Right.

Ms. **McIntosh** [continuing]. Kind of care.

Chairman **Miller**. If you wanted to do it, that is my point.

Ms. **McIntosh**. Exactly.

Chairman **Miller**. The way the funds are now set up,

Ms. **McIntosh** [continuing]. That is correct.

Chairman **Miller** [continuing]. The latency period will run before you assemble the funds necessary.

Ms. **McIntosh**. That is correct. There is another issue that involves teenage mothers and their babies. Under the existing foster care regulations, you can only pay the foster care rate for the mother, not for the baby, when placed with the mother in the same placement, which is a discouragement for placing the mother and baby together. It is a discouragement for institutions or for group homes or foster parents, and I think this is a compounding problem, which we will be asking Congress to help us address.

Dr. **Villarreal**. If you could, and we are putting together, we are trying to put together, a model where we have a home for IV drug using moms and their kids, and using that system and we are going against all odds, I mean,

Chairman **Miller**. Yes.

Dr. **Villarreal**. And, so, we are putting together . . .

Chairman **Miller**. You cannot build a home with six normal foster children and a family in a neighborhood in this society. Where are we going to put these people? Are you going to take over the Biltmore Hotel in L.A.? I am serious.

Dr. **Villarreal**. I am serious, too. That is what we are going to have to do. There have to be new models. We have to look at the structure completely different. These are all answers and they are not going to fit.

Chairman **Miller**. Mr. Stark, I am glad you are on Ways and Means.

Dr. **Villarreal**. One of the problems in terms of the whole housing issue for people with AIDS, there have been community housing programs, the Shanti program in San Francisco has several community houses where people with AIDS who do not have adequate housing elsewhere can go and live. The problem is they are not set up for women and children.

Now, as we are beginning to have women affected with children, we need those kinds of resources.

Chairman **Miller**. But why the suburbs?

Dr. **Villarreal**. Walnut Creek is not ready for it. You are right, but——

Chairman **Miller**. But, trying to think in the non-hysterical sense, if you look historically at how you have addressed a number of these problems, until they become middle class issues, there is no response from the Congress of the United States.

Dr. **Villarreal**. That is right.

Chairman **Miller**. I do not think you want to wait until this one becomes a white suburban middle class issue like we are doing with child care. This happens to be a little different.

We have dealt with drug abuse, teenage pregnancy, and child care in the suburbs and there is a shared experience between urban and suburban, rich and poor, middle class people that Congress does not respond to because then you have a critical political mass.

If that happens here, we are going to have a critical mass. I know, the ball is in my court. I am done. I just have oversight. I do not have any legislation.

Chairman **MILLER**. I am just trying to think. I remember ten years ago in my early involvement with asbestosis and mesothelioma, a number of my colleagues, fortunately one of them has since been defeated, wanted to know how many bodies there were with asbestos in the schools. I tried to explain thirty years latency, twenty years latency, and the theory basically was we did not do anything about asbestos in the schools until there was a body count. I think that that is a prevalent view in the Congress of the United States, because we still believe that society is driven by the deficit. This is an example that it is not, and I am just terribly concerned about how we will put together a model, whether it is in curriculum or research or treatment, that can be translated into action, given the historical way the Congress has treated these problems and the historical models that they have used.

Most of the descriptions of how AIDS confronts various sectors of our society that you and the previous panel have outlined here simply do not fall within the traditions of how we try to manage the social service caseload.

Dr. **SWARTZBERG**. Mr. Miller? I would like to throw out one more bottle.

Chairman **MILLER**. I cannot wait.

STATEMENT OF JOHN SWARTZBERG, M.D., F.A.C.P., CO-MEDICAL DIRECTOR ALTA BATES/HERRICK HOSPITAL, AIDS SERVICES

Dr. **SWARTZBERG**. My name is John Swartzberg, and I am a practicing physician here in Berkeley, and my specialty is both internal medicine and infectious diseases.

Because of that latter specialty, I have been taking care of patients with AIDS since the beginning of this epidemic, and I am the only one on either of these two panels who is a practitioner, and I would like to give you some of the things I have learned about the problems.

Excuse me. I apologize.

Dr. **VILLARREAL**. I take care of AIDS patients as well.

Dr. **SWARTZBERG**. Okay. Pardon me. I am in agreement with everything you said.

The thesis that I would like to propose to you is from what I have learned is that the current model for the private practice of medicine in our society is inadequate to care for patients with HIV infection. I have learned that from personal experience, and I would like to illustrate that point briefly by telling you about a situation that occurred to me in my practice just a very few months ago with a young man coming in and asking to be tested because he was afraid he had been exposed to HIV and that his greater concern was that he had exposed his wife, and there was even further greater concern that he had just impregnated his wife approximately three months before. Tragically, all three, or at least two of the three I know of now, the husband and the wife are both HIV positive.

The point I am making with this illustration is that this unit of two people, soon to be a third probably infected with HIV, has required two internists, an infectious disease specialist, an obstetrician, a pediatrician from the purely M.D. side of the perspective.

There have been two psychotherapists involved in the care. There has been a social worker involved in the care, and there will be another social worker involved in the care when the baby is born.

That is not a model that traditional American medicine has set up to deal with. For all of them, there needs to be a new model or we need to turn over the care of AIDS patients purely to the public sector.

I would strongly disagree with that latter approach because it essentially says that if you have cancer or if you have heart disease, we have a perfect model for you to be mainstreamed into American medicine, but if you have AIDS, there is something different about you and you have to go and receive all of your care if you want quality care, integrated care, that type of care, you have to go to the public sector, and I think that is sending a very bad message to our society.

I wanted to make sure to inculcate that into you. What I am suggesting is that some of the funding that has to come from our society has to be directed towards finding new paragons within the private sector of medicine to take care of patients, integrated approaches, that deal with the bulk of the population that continues to use private practice as their mechanism of health care. That is all.

Mr. STARK. Doctor, there are some fairly large HMO-type deliverers of medical care in this area. How do they handle this? If they had the same case that you just described, how would the large HMOs in the Bay area deal with it?

Would they provide all of this?

Dr. SWARTZBERG. The HMOs would be "stuck" if that young man that I mentioned was his patient.

Mr. STARK. The man and the child were all in the same plan.

Chairman MILLER. How are they going to manage that case?

Dr. SWARTZBERG. They are going to manage it with a great deal of difficulty, and they probably cannot afford to financially manage that. They cannot at least afford to manage very many of those.

Mr. STARK. What are they doing? This must come up. If you know. I mean,

Dr. SWARTZBERG. I cannot speak directly for the HMOs in terms of how they would handle that, but they are obliged by law to take care of the patient if they were a member of the HMO prior to their developing the disease.

The problem really I see is that it is going to change the marketing strategies for HMOs in general. Already, HMOs disenfranchise a great deal of our population because they want to pick the healthy people, which is a whole different topic.

Chairman MILLER. Do not start.

Mr. STARK. I mean this to be neutral. I am just curious.

Dr. SWARTZBERG. I think what will happen is it is going to further disenfranchise people because the HMOs are going to avoid taking in people who are going to have markers for being infected with HIV.

Mr. STARK. What is the best way? In terms of your experience, is it to have this multiplicity of practitioners or would you develop, because it sounds to me like you are going to have enough of a patient load, to develop people who specialize?

I do not mean necessarily just governmentally-financed types of providers, but are you talking about the possibility of seeing within the medical community, the health care delivery people, a place like we used to do with tuberculosis? Are we talking about sanitariums or——

Dr. **Swartzberg**. Well, I have a couple of comments. The first is that I cannot—I am not wise enough to propose to you a model that will work for the care of AIDS or HIV-type of people in our society. What I am proposing is that I think there are a variety of different systems that we have got to experiment with currently and then find out which of those work and build from there.

The plea I was making was that we are going to have to look at care for these folks on an integrated basis, both in terms of the public and private sector, who need more levels.

You have been hearing a lot about the new models that are proposed or at least a plea for new models in the public sector. There has been a desperate need for new models in the private sector if we are going to manage.

In terms of hospitalization, I feel very strongly that we have to approach patients who are infected with HIV no differently than we approach anybody else with any kind of infectious disease or any other kind of disease process, that we do not create sanitariums, we do not create institutions that solely take care of AIDS patients.

I think that that is a very dangerous message to give to our society. I think we should get rid of the archaic anachronistic concept of leprosarium. I do not think that is the way to go for care of our patients.

I also would like to comment on one other thing that I think was being said. I am not quite as optimistic as Ms. Boxer, but I am somewhat optimistic that I think it is terribly important to read the history of infectious diseases on Western civilization to gain the perspective of what our chances are of controlling this epidemic with education being the major thrust right now.

There is no, to my knowledge, there is no example or model for a sexually-transmitted disease from the beginning of our civilization going back to classical times that has been prevented, and I think Dr. Benjamin's comments about syphilis on the rise again can be interpreted in another way, and that is that education is critical, but prevention of a sexually-transmitted disease has never been achieved in Western civilization.

Chairman **Miller**. Anything else?

Mr. **Barrick**. Mr. Stark had asked some questions here earlier on numbers and costs per case of care, and although the numbers of children with AIDS is not significant and, therefore, is not useful in terms of statistical treatment, the adult costs of care now range anywhere from $80,000 per case, which is the San Francisco model, which attempts to keep the client as much possible out of the institutional setting, to a high of a $140,000 per case in New York.

Those are average numbers. I think that in terms of predicting a relationship between the cost of adult care and the cost of care of newborn or pediatric cases, because of the difficulty of children and newborns in communicating distress, it is far more likely that, you know, given their acuity, intensive care units are going to be used not for traditional reasons, but solely as a product of the acuity of the care involved.

This is consistent with someone's suggestion that in toto the care of children will be more expensive than the care of adults.

Chairman **Miller**. Thank you.

Well, thank you very much for a quick survey of what we are going to have to contemplate, and thank you for your help to the committee, and I am sure that we will be back in touch with you, so to speak.

Thank you.

Chairman **Miller**. The committee stands adjourned. Again, let me say to those in the audience, some who wanted to testify, the record of this hearing will be held open for two weeks, so written testimony or comments can be submitted to the Select Committee in Washington.

Thank you. Thank you again, Alta Bates.

[Whereupon, at 12:41 p.m., the committee was adjourned.]

AASK, AMERICA
February 21, 1987.

Re written testimony, field hearing, Berkeley, California

Congressman George Miller,
Chairman, Select Committee on Children, Youth and Families
Washington, DC.

Dear George. Aask America/Aid to Adoption of Special Kids has placed over 4,000 special needs children in adoptive homes since its founding in 1973 by Robert and Dorothy DeBolt. The services of Aask America are free to adoptive families. Aask America has internal and external computer data records on thousands of homeless children and thousands of qualified adoptive parents willing to adopt children with health problems. A hallmark of our service is the matching of special children with their prospective parents. We are a licensed adoption agency and we have an Aask America network of 24 field offices serving all 50 states.

Aask America's expertise is in adoption and foster-care services, not Acquired Immune Deficiency Syndrome. Within the last few months we have been asked to match abandoned AIDS infants with prospective parents, and we have done so. We expect many more referrals of AIDS infants in the months ahead. We elect to be pro-active in planning and providing services to this new population, rather than to simply add to the case-load an existing service delivery system.

Our plan includes these elements which we will have in place by July 1, 1987:

1. National computer registration of children born with AIDS who are in need of an adoptive or foster home.
2. National recruitment of prospective parents for these children, and computer registration of qualified applicants.
3. Appropriate matching of children and parents for the purpose of foster care and adoption.
4. Research, printing, and dissemination of a national and regional resource directory of social and medical services for all families with, and agencies serving, children with AIDS.
5. Appointment of a National Board of Reference of experts in dealing with the emerging issues of homeless children with AIDS, which will recommend policy direction to Aask America's National Board.

Since Aask America has existing resources in place including experienced professional staff, computer systems, and a national network of service centers, we propose to implement this project with minimal additional support from public and private sources.

We hereby request the following assistance from the House Select Committee on Children, Youth, and Families:

1. Recommendations of possible appointees to serve on the National Board of References.
2. A copy of the Committee's mailing list of public and private organizations which have an interest in this problem, to be the basis of researching a directory.

3. A letter of endorsement from you, as Chairman, which we could use to 1.) support our proposals for additional funding from public and private sources, and 2.) encourage county and state officials with custody of AIDS children to register these children with us for the purpose of adoption and foster care.

Thank you for allowing us to communicate our plan to the Committee, and we look forward to a meaningful level of coordination.

Cordially,

John D. Badger,
National Director.

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